

Of Research and Action

*Contribution of Non Governmental Organizations
and Social Scientists in the Fight against
the HIV/AIDS Epidemic in India*

Edited by
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Belatedly, India has recognized the gravity and magnitude of the pandemic. The official figure of 75 000 persons infected by the virus on the Indian subcontinent, at the end of 1997, reflects only the tip of the iceberg. While the national policy to combat AIDS is still in the project phase, a certain consensus is being established that the spread of the epidemic is one of the most virulent in the eastern part of the world.

Within the period of a few years, considerable sums have flowed to India from international sponsors for the social prevention of AIDS, notably to Tamil Nadu and Mumbai which have become two favoured places for the introduction of numerous projects. At the same time, albeit with a certain time-lag, research in the human sciences on the risk factors and socio-cultural context of sexual behaviour have developed hesitantly and not without institutional difficulty.

Until present, little is known about the plethora of NGOs which are appearing foremostly in the cities. Research, which is equally scattered and primarily financed by outside agencies, has not been the object of systematic assessment. A national workshop, organized by the CNRS laboratory "Societies, Health, Development" in Bordeaux, the National Agency for AIDS Research, the French Institute of Pondicherry and the Indian Society for Environmental Health in Madurai, presided over by Dr. S Subramaniam, brought together for three days some one hundred persons from diverse spheres in order to undertake a provisional and selective assessment based on case studies.

Based on a collective reflection, the present volume makes no pretence of presenting an exhaustive inventory, inasmuch as the subjects broached are vast, but aims at providing reference points regarding the question of the implantation of NGOs: the position of NGOs in the national and international political environments, the diversity of their activities and the introduction of strategies, their contribution with regard to medical, social and ethical aspects, their engagement in the fight against discrimination and for the assistance of afflicted persons. Beyond these themes, particular attention is given to the relations between researchers and groups which intervene in the field. Ultimately, the main subject is the relevance of research and its applications, views upon which are far from unanimous in India, or elsewhere.

How and to what extent can collaboration exist among the specialist from the social sciences, the NGOs and the government, and under which conditions? What are the possibilities and the limitations of a researcher in making his work known? Such are the questions which this work attempts to circumscribe in the conclusion.

Introduction

The emergence of NGOs in the fight against AIDS in India

In 1990, ghostly signs appeared in the towns of the South showing a white skeleton on a red background with a notice in vernacular language stating that AIDS was a disease contracted outside the family which irremediably destroys. The HIV/AIDS epidemic was far from being a major concern and information was scarcely accessible, either to the population or to the medical corps and public health representatives.

However, the first case of AIDS have been identified in 1986 in a hospital in Vellore, in Tamil Nadu, and since then the number has increased in all corners of the country. Nevertheless, the rare cases detected at that time were viewed as anomalies confined to, in one way or another, deviant persons who had been in contact with the outside world. An analogous attempt to relegate AIDS to beyond the borders was to be found in newspapers which clearly differentiated the number of foreigners infected by the virus from the number of Indian citizens who were infected. Some conjured up an attempted plot against India, while others evoked the existence of a biológico-natural and cultural protection of the country.

It was despite this context of denial that the first local NGOs began to integrate the social and individual prevention of AIDS in their programmes. Since 1990, associations have been emerging which are devoted solely to the fight against the epidemic. It would be strenuous to imagine the extent to which the pioneers in this field, at least in the South, had to confront and struggle against ostracism in order to assert their activity, among the population as well as within their own social and institutional environment. While the government procrastinated and displayed no clear position regarding the policy to be followed respective of AIDS, international agencies began to become concerned as to the impact of the pandemic on the Indian subcontinent and announced their intention to finance intervention projects and to encourage, *de facto*, the development of NGOs.

Considerable sums were allocated to a plethora of associations which continued to grow in number, particularly in certain privileged states, such as Tamil country. As for the public health sector, it was scarcely encouraged, apart from a few specific actions, to introduce AIDS into the framework of the primary health care network. This being the case, the development of NGOs was accompanied by an atomization of activities in social and individual prevention of the epidemic on the Indian subcontinent, at the cost of the creation, which was yet to come in 1998, of a balanced and coherent national policy.

The aim of this work

The present volume resulted of a national seminar, held in Pondicherry on 7-9 November 1997, on the role and involvement of NGOs in the social prevention of AIDS, and on the theoretical and practical relations between action and research. This workshop was organized by the French Institute in Pondicherry, the National Agency of AIDS Research in

France, and the CNRS laboratory "Societies, Health, Development" in Bordeaux, in collaboration with the Indian Society for Environmental Health in Madurai.

The need to organize this seminar corresponded to a crucial absence of information on Indian NGOs, considered as the spearheads in the fight against AIDS in India. Little was known about these disparate associations, either on the level of their organization, their territorial implantation, their ideologies, or regarding their practices, the quality of their relations with state authorities and, more importantly, with the population. An even greater lack was the absence of knowledge concerning the strategies which were implemented, the conditions in which the projects were introduced, as well as their evaluation. A corollary question immediately arises: beyond the logistical means of which the NGOs avail, were their various activities based on a prior knowledge of the conditions and situations of the lives of the population whose behaviour they wished to change? In other words, what place do they accord to research, to the acquisition of the latter, and what have been the collaborative experiences between specialists in the social sciences and activists?

There are many complicated questions evolving around the theme "research and action", but it is imperative that rudimentary answers be provided at a crucial time for the country when the main lines of a future policy for the fight against AIDS are being meticulously drawn. To do this it was decided, on a very modest scale, to bring together a number of persons (roughly one hundred). The number of the participants remained small for reasons of budgetary constraints, as well as out of a concern to create an atmosphere favourable to exchange, to enable of a dialogue between actors from diverse geographical, professional and social horizons.

This work makes no pretense whatsoever of taking stock of such a vast problem in a country containing nearly one-fifth of the world population. The approach chosen at the time of this seminar was to centre reflection around the difficulties encountered by NGOs at the level of the implantation of their projects, as well as concerning their relations with the institutions of the country. It appeared to us at the outset that the NGOs were not simple relays, as is said, but veritable private, independent institutions which must give only scant account of their work to the authorities other than their financial accounts and a summary presentation of "targets and achievements". Until present, and contrary to what is taking place in other countries of the South, there seems to be little complementarity between the Indian health system and the sporadic and selective activities of NGOs in India.

The purpose was, therefore, to give rise to a critical assessment through the presentation of a few cases. Effort was taken to facilitate free discussions, to give the word to one and all, notably to persons who could express themselves only in a vernacular language. Academic colloquia on AIDS are presently abundant in the country, but meetings are rare which enable those in the field to share their real-life experiences. In order to cover this lack, we hoped to generate a reasoned analysis, and have demanded a certain ability of the participants to put their own work in perspective. From this point of view, it is necessary to acknowledge that the success was mitigated, notwithstanding the open and constructive discussions which took place.

This volume undertakes to transcribe the essential of what was presented, as well as certain discussions which add a critical dimension to the words of the speakers. Some fifteen cassettes

were deciphered and transcribed in English. In terms of content, the intent of this work was to present to a public which is not familiar with India the major tendencies concerning the state of research and the past and present orientations of NGOs on the subcontinent.

Presentation of the work

This volume is organized in five parts, of heterogeneous size, corresponding to the five large themes which were discussed and debated in the course of the three-day seminar. A supplement at the beginning of the seminar served as a general introduction to the themes which were subsequently discussed.

Each part of this book is devoted to one theme and presents an ensemble of contributions from which the reader will be able to observe the diversity ranging from personal testimony to communications of a scientific character. The contents are also unequal and numerous representatives preferred to intervene in an informal manner when it appeared to them appropriate and opportune to speak. Let us note in this respect that a number of NGOs insisted on speaking "from the heart" of their involvement rather aloofly presenting decontextualized data. Some discussions of a provocative but reasoned nature were entirely transcribed. Others, due to constraint of space and out of a concern to avoid repetitions and the clichés which inevitably appear, were abridged or even eliminated. The conclusions of the seminar were in part discussed at the end of the three days. It was only some months after the seminar was held that a small group of persons met again to elaborate the successive conclusions.

The first part constitutes an introduction by scientists, medical doctors and a representative of the National Committee for Women. It was a matter of exposing productive points of view pertaining to local problems respective of and complementary to NGOs and research in the social sciences.

The second part endeavours to reveal the position of the NGOs in the national and international environments. Insofar as the greater part of the funds allocated for the social prevention of AIDS and the care of the sick comes from international agencies, it is useful to look into the logics of the functioning of NGOs respective of the multiple constraints exerted on them, both on the macro and the micro levels.

The third part considers the role of NGOs in regard to the ethical, medico-legal and socio-epidemiological aspects raised by the AIDS epidemic. In 1998, there still does not exist, contrary to Africa, a committee on ethics, whether at the national or regional level, and only a few scattered activists are engaged in the fight to uphold the most fundamental human rights. The concepts of voluntary detection, anonymity, shared confidentiality are but slogans and are rarely respected, while the notions of pre- and post-test counselling and psychological support assume very different meanings from what is understood thereby in the West and in Africa. Thus, for many representatives of the medical corps, the notion of medical secrecy subsequent to the announcement of seropositivity proves to be inoperative in a country in which the family and society are placed in the foreground to the detriment of the individual. Our intention is not to judge, but to understand the argumentation advanced by a not negligible part of the doctors and public health officers. The socio-epidemiological dimension which some associations

attempt to cover is also not to be neglected, because it illustrates a certain malaise in India in choosing between the obtaining of epidemiological data in the general population and a preference to focalize the intervention campaigns on the so-called "at risk" populations. Others manifest doubts regarding the necessity to create a national system for the compilation of epidemiological data, given its cost, and propose to at first centre efforts around the struggle against discrimination, exclusion and stigmatization which are perceived as brakes on any ulterior effort to change practices in the population.

The fourth part, which contains the largest number of contributions and which was the richest in discussion, takes up the often conflicting relations between research and action. The phenomenon is not new. It was nevertheless necessary to consider it after having observed among certain NGOs the thoughtlessness with which they envisage their intervention programmes. It was, therefore, imperative to justify and legitimize, not research in itself, but the necessity to understand the facts, to observe the social dynamics which are at work and condition the introduction of development projects. With the advent of AIDS, research in the human sciences has been in full expansion. A decade ago, to undertake a study of sexual behaviour in India meant defiance and provocation. Today, it is a norm. Until very recently, studies remained extremely standardized and responded to a concern to obtain general and quantifiable information. There resulted a certain methodological and theoretical poverty which scarcely enabled one to obtain a veritable knowledge of spatial, economic and sociocultural determinants of the epidemic. Faced with the inadequacy of certain research work undertaken on a national scale (notably on groups at risk), research is diversifying, becoming more profound, exploring new terrains and attempting to render its knowledge accessible to decision-makers and other developmental actors, bringing about a certain legibility and clarity in the enunciation of results. At the same time, it is increasingly asked of researchers in the social sciences to evaluate the programmes, to study their feasibility and their acceptability. The majority of persons coming from different disciplines and present at the workshop were researchers invited to reflect on these last questions.

The fifth part of this book gives the word to persons afflicted with the HIV virus and AIDS, as well as to organizations which take care of sick persons who have been rejected by their families and their social environment. It is, therefore, essentially a matter of testimonies in which individuals speak mainly of their own experiences. Such occasions are rare in India where, even in institutions, one is still reluctant to invite seropositive individuals because of the stigma raised by the epidemic.

The sixth part traces the diversity of activities of NGOs, experiences in the establishment of projects, attempting whenever possible to accentuate the lesson to be derived from their failures. If the NGOs are numerous, the question was to know if their field of activity was homogeneous and if their ways of viewing the prevention of AIDS differed to a greater or lesser extent. One observation forces itself upon us: the NGOs focus on particular aspects of the epidemic and rarely adopt an encompassing approach. This is less the consequence of clearly expressed volition, than the result of a set of constraints (financial precariousness, short-term projects, etc.) which induce them to eschew temporality. Rare are the NGOs which say they are able to act in accordance with their ethical convictions. Despite the implicit instructions of the sponsors to subscribe to a small number of "models" which are deemed to be efficacious, it is not precluded that the actors working in the field demonstrate

sagacity, persistence and innovation and accommodate themselves to the constraints imposed from above while taking into account the needs and doubts felt by the people as well as the social forces acting on them.

One sees that the problems raised by the epidemic on the Indian subcontinent may be perceived of the same nature as elsewhere, but are posed in different terms because of the scale and the sociocultural and political specificity of the country. The conclusion of this book takes up the main ideas evoked during the seminar, reflects upon what was not said and attempts to reformulate the problems considered on the basis of the information acquired. Lastly, the authors endeavour to define the repercussions of such a seminar. Was it useful and if so, for whom? How and under what conditions is one to promote such colloquia so that they generate new initiatives without, however, resembling absurd parades in a costly show where the new celebrities of AIDS, equipped with incantatory discourse, march past? AIDS compels an involvement at the same time as it supposes an ethics.

Frédéric Bourdier

" It is not a new reading of society that must be
undertaken, society must be re-written"

Robert Mallet, *Apostilles in* Notes dédiées à Jean Poirier, PUF, 1997

*To William, Alice and Sylvia
and many others*

Introduction

Dr Subramaniam : It gives me very great pleasure to welcome you from all regions of India to take part in this workshop on NGOs involvement in AIDS/AIDS prevention and care. The Indian Society for Environmental Health (ISEH) from Madurai and the French Institute of Pondicherry together have attempted to gather various personalities involved in one way or another in the struggle against the epidemic. Such a meeting responds to the urgent need to arrive, during these three days, at a relevant analysis of the social problems we have all faced so as to better understand the epidemic. Nobody would deny the necessity of a national policy which has to be decided by the government agencies; but, we all know that their scope of action is limited. On the other hand, NGOs are supposed to be in a position to reach the lowest strata of the society, which are usually not reached by national bodies.

For instance, many of you interact with commercial sex workers, try to understand their level of vulnerability in a patriarchal society, and try to empower them by promoting awareness, preventive methods, safer sex and social rehabilitation for those who want and who are in a position to be rehabilitated. One of the main objectives of the NGOs' action is to try to prevent people from becoming infected by informing them not only about the biological risk represented by unsafe sex, but also about the extent of mental degradation resulting of drugs. Places like Manipur, Mizoram, and to some extent Assam, have become notorious for the dramatic number of intravenous drug users (IDUs) who have become HIV-positive.

Mumbai, which is the commercial capital of India, now has more than 50 000 HIV cases. Madurai, from where I come, is known not only to be a pilgrimage centre, but is also noted for its prostitution. The "cultural" city of the South has a reputation for being a permissive place for sex, and for having an evident and highly complex network of prostitutes, pimps and other persons involved in the sex trade. At present, more and more communication areas where lorry drivers are centred, like Narmakkal in Tamil Nadu, are challenging the prevention campaigns. In fact, the country as a whole faces the epidemic, whether rural or urban areas, southern or northern states. Nobody, irrespective of class, sex and caste, can think to be safe. Again, that is why we have come together to exchange the ideas and learn from each other's experiences in order to make a safer place to live for everybody.

F. Bourdier : Along with the Union Territories of Delhi and Pondicherry, twelve states of the Indian subcontinent are represented in our assembly : Rajasthan, West Bengal, Orissa, Maharashtra, Goa, Madhya Pradesh, Manipur, Mizoram and the four South Indian states of Kerala, Tamil Nadu, Karnataka, Andhra Pradesh. One of the purposes of the workshop is to give a bird's eye view of the national situation and, most of all, to interact in a constructive way. I have been very insistent that this seminar be conducted in an informal way: no very important people (VIP) will preside at the seances, nor will there be any other unnecessary speeches. There will be no ceremonious functions such as are usually held at symposia in India. I do hope you have come not only to listen to others and present your own ideas, but eventually to learn from the experiences of others to evaluate the potential collaboration among people of different backgrounds. For my part, as a researcher in social sciences, I am interested in knowing about

the nature of the problems that NGOs, government representatives and activists are facing both at the designing stage and at the implementation stage of the projects.

The particularity of this assembly is that it is composed of persons with extremely varied occupations: doctors, epidemiologists, public health officers, health administrators, while others are members of NGOs, representatives of international agencies, researchers, community delegates, human rights activists, legal aid advisors. Due to our profession, each one of us is dealing with social aspects of the HIV/AIDS epidemic, most probably from a particular perspective. As far as the workshop is concerned, the diversity of our different approaches, our different perspectives, is undoubtedly our strength. Through our combination, we have the potentiality to facilitate the emergence of new ideas, if we are ready to accept the arguments of others.

Those who have joined the seminar are mostly from the private sector. In the field of HIV/AIDS, NGOs encompass a vast domain : from focus interventions to more integrated approaches in which the epidemic is just one of the components. On the other side, social scientists who are present in the assembly are generally not directly involved in action. However, whether they are sociologists, anthropologists, geographers or psychologists, they have the capacity to analyze the facts and figures of the Indian situation in as objective and neutral a way as possible. Ultimately and theoretically, their findings should provide some insights. They may enable the deciders to orient their programmes, and they may help the social workers to have a better understanding of the various sociocultural contexts in which their actions are supposed to take place.

After a few years in India, and after numerous contacts and close relations with NGOs, I have come to realize that there are a set of misconceptions about: 1) the nature of the research; 2) the relevance of research; 3) the purpose of research; and 4) the difference between social action and social research. One of the final objectives of the seminar is to clarify what potential benefits and advantages one may get by taking into account the findings of social research. During these three days, we are going to review a state of the art of NGOs' various implementations strategies. The panorama will not be exhaustive insofar as only a limited number of NGOs are represented.

Lastly, I have to point out that due to 1) the constraints of time, 2) the importance to be given to constructive discussions and, 3) the large number of papers received, it will not be possible to give everybody an opportunity to present a paper. It has been decided to try to avoid repetition, similar projections, common statements. Priority will be given to innovative papers. But more important than the papers themselves, the outcome of the seminar depends on everyone's participation.

Part One

Points of View of :

Leaders of Community-Based Organizations

Social Researchers

Doctors

From Understanding to Action

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Nobody can deny that if AIDS is the physical manifestation of a biological disorder, the epidemic is the reflection of a social phenomenon. Whether transmitted through sexual fluids, blood, the injection of drugs or from mother to child, the propagation of the virus depends on specific human behaviour. The virus does not "jump" on people. The specific behaviour may change from one society to another according to the sociocultural context, the state of politico-economic development and local circumstances. Identification of these societal components is, therefore, fundamental in understanding how and under which circumstances HIV/AIDS is spreading.

Once it has been admitted that the progression of the epidemic is strongly connected with the social and technical context in which human practices are rooted, sexual behaviour plays an essential role, even if other modes of transmission are too often forgotten or neglected. Little is said for instance about breast-feeding contamination which has now been definitely proved: in many developing countries there is still nothing done for the infected mothers giving birth, in terms of prevention policy, and recommendations remain elusive. A few years back, WHO recommended not to stop breast-feeding by the HIV-positive women in developing countries, a statement - more political than medical - which would have been unacceptable and would have created havoc if implemented in a developed country. Since a health system is a political system, we have to keep in mind that prevention policies are neither objective nor impartial. Different options are theoretically possible. In India there has been a combination of constraints and choices - both external and internal - to lay emphasis on fidelity, abstinence and in the last resort on the use of the condom, while elsewhere the objective has been to promote how to *enjoy* a safer sexuality, to promote alternative sexual practices. Sociocultural and economic factors influence these choices and constraints and can also be used as a justification, a pretext, to reinforce social disparities, gender inequality, group discrimination. Here arises the phenomenon of social re-appropriation: this means that a government, an institution, a local body or a particular group will take advantage of the outbreak of the epidemic to strengthen its position and pinpoint another group or certain individuals. In Africa for instance, it has been observed that in stratified societies the elders (seniors) who were losing their social power with the younger members (juniors) have managed, in the time of AIDS, to restore the traditional power relation, insofar as unmarried juniors were *assumed* to endanger society by having unsafe sex practices. In India, our research conducted among urban middle-class women has revealed that sexual discrimination was intensified towards those who were socially and spatially mobile. Women who tend to have other professional occupations than as housewives are more likely to become victims of stigmatization. Similarly, men accuse women of spreading the virus because of their inherent biological constitution: recalling that in the same way venereal diseases were previously called *pomballe seeku* (woman's disease) in Tamil society.

Regarding risk practices, it has become common to argue that the control of the epidemic will depend on the limitation or reorganization of these practices. The discovery of a new therapy now available in America and Western countries is like a miracle but, due to its incredibly high cost, and to the logistical organization that is required for regular drug provision for the patients,

it will never be available or affordable for most of the infected persons in India, if we except a handful of privileged persons from the upper classes. One has to remember that foreign pharmaceutical companies have hardly been interested in promoting cheap drugs for developing countries, and there is no sign which would indicate a change in the world economic policy in the time of the epidemic. And even if this were to happen one day, whether through a vaccine or an effective treatment, technical measures will never be sufficient to fight against the advance of the pandemic. This becomes particularly relevant in Asian and African countries where the public health delivery system is suffering from drawbacks, and where social and gender inequalities operate as constraints on the generalization of health care and on adequate and uniform access to it.

That is why social prevention is "condemned" as the main focus for any HIV/AIDS policy, even if every government has to encourage medical research adapted to its own capacities in relation to its economic, social and political characteristics. We must, however, explain what we mean by prevention. Is it just to make people aware of the disease, and tell them what to do, or what not to do? Social and individual prevention cannot be restricted to a mere communication process. In addition, there is the question as to whether the concept of prevention will be confined to its narrow definition, or extended to embrace a more holistic approach. For example, fighting against discrimination, encouraging adequate counselling and integrating HIV-positive persons into society can also be considered as further preventive measures.

While the identification of practices which are "at risk" is one aspect needed for the comprehension of the diffusion of the epidemic, we cannot reasonably make a pretense of taking on a complex problem just by touching it with the tips of our fingers. Practices are the consequences of existing structural and fluctuating situations, and the social dynamics that contribute to the spread of the epidemic must be discovered. We have to go to the roots, act as geologists and psychoanalysts, in order to demonstrate the need to focus project interventions in such a way as to take into consideration the socio-economic and cultural context which gives birth to the moment, place and conditions of vulnerability to HIV/AIDS. A concrete example taken from our research project will be discussed in the next session.

Various disciplines and bodies have been called upon to cooperate in the struggle against the epidemic and, as that is the purpose of this seminar, I would like to provide a few elements for reflection related to the human sciences and the participation of NGOs.

On the one hand, several contradictions are observed if we look into the mutual contributions of medical and social scientists. This is so, first, because AIDS is a challenge to biomedical science. Even if everybody agrees that the epidemic is related to society, development, culture and economy, there is an obvious attempt by the medical sector (specifically microbiologists in India) to control what is to be regarded as a social problem. This is not to blame doctors and other medical researchers. They have been the first to be confronted with infected patients, to realize the problem and the magnitude of the epidemic. It is human and justified on their part to try to counteract the disease. But improvisation can be worse than doing nothing. Because the situation was urgent, they were convinced that emergency solutions had to be adopted. I remember a well-intentioned doctor in Coimbatore who told me that if AIDS is spreading quickly, health planners have to act and change people's behaviour more quickly: a kind of race. The intimate certainty that there is no time to waste has led some medical personalities, along with paramedical staffs and social workers, to launch prevention projects

without always being aware of the reality faced by the people, the day-to-day difficulties they have to solve, their perceived priorities, and without recognizing the social contexts and circumstances liable to prevent the people from modifying their behaviour, in spite of a newly acquired awareness. Here, social scientists should have something to say. Their skill is supposed to enable them to provide a comprehensive understanding of social situations, to identify the dynamics of society, to design a cartography of the social structures in order to detect individual and group vulnerabilities regarding the HIV infection. Anthropologists, human geographers, and sociologists possess tools and adapted methodologies to analyze the facts and figures of a given society. They know that a society is not a mere addition of individuals, but is a living entity having its own rules which transcend individuals. A reality which is too often forgotten in many programmes, in which, I would dare to note, one will find a medical representation of the social: a preconceived idea is that individuals are negatively influenced by taboos, beliefs and superstitions which discredit prevention programmes. One has to overcome these "mentalities" in order to guarantee the success of the launched action. Another medical representation is the behavioural conception of human nature: human beings are perceived as rational and are supposed to act according to logical mechanisms. In other words, if new information is transmitted, then the person will grasp it, integrate it, digest it and change his behaviour accordingly. This false conception makes sense, however, for those whose intervention projects rely on the belief that by communicating a new message, people will operate differently if they receive the message in good will. Maybe it is necessary, but it is not sufficient. It means forgetting that human beings are made of flesh and blood, that they are unpredictable, changing and "irrational". As a counterpoint of this supposed mechanical behavioural attitude, one session will be devoted to explaining what specialists of human sciences mean by 'social', what the 'social' which they claim to study is, and what the specificity of social research can be when dealing with HIV/AIDS.

Furthermore, people live in a material and social environment which strongly determines their way of thinking. They already have their problems, and they do not have the same priorities as the developer and the policy-maker would like them to have. Coming to a slum in Chennai, one social researcher involved in my project arrived at the conclusion that people were more preoccupied by mosquitoes than HIV because they cannot sleep at night and children are badly affected by scratches. Even in the time of AIDS, and in spite of a generalization of awareness, the precariousness of living conditions appears to be a more important issue for the deprived population. Then, AIDS appears to be just one more killer disease among others. So, where must we start? Are we dealing with a disease or with a manifestation of underdevelopment and poverty? We will return to this point in a coming session.

Despite the theoretical recognition given them, it is surprising to observe that the social sciences do not benefit from this acknowledgment and, in reality, are not always welcome in the field of intervention. This is neither the place nor the moment to analyze the reasons behind this apparent paradox, but we may wonder whether government, private bodies and representatives of biomedical sectors made a judicious choice by avoiding social analysis under the pretext that there is no time, or that human scientists will only complicate the debate by hair-splitting. Action is important, but is it possible to economize on understanding before initiating an action? Despairingly, social scientists are in constant mourning. Their work is most of the time neglected, if not refused when it becomes too critical. All doctors will, however, agree that prevention is better than cure. Only when things do not improve and when projects are failing, are social

scientists called to the rescue; and the detractors realize *a posteriori* the potential relevance of their contribution.

On the other hand, the involvement of NGOs in the field of HIV/AIDS prevention and care is a direct consequence of the ethical necessity to *act* and approach various populations in order to create awareness, knowledge, empowerment, and to suggest that they modify practices, attitudes and modes of thinking that can lead to HIV exposure. Union and State governments, after a period of denial, are taking responsibility for the planning of different orientations of the national programme for the struggle against AIDS. But, respective of the nature of their official, administrative and national positions, they need more flexible bodies to extend, complete and implement the decisions coming from the "top". One assumption is that NGOs should be closer to the population, more aware of the existing realities and problems faced by groups and individuals. They can act as intercessors between government and the civil society and, by receiving feedback from what is going on in a particular area among a particular group of people, they are in a better position to adjust, innovate and create original solutions to interact with the people. Information collected from the "bottom" enables NGO activists to intercede and, if justified, call into question unrealistic targets and inadequate policy orientations. The question is not to know whether development has to start from the bottom (in the people's hands), or at the top (in the deciders' minds), as has been debated for years in most of the developing countries, but to find a compromise, a negotiation on the basis of the constraints with which government and people are confronted.

Of course, this remains purely theoretical because the majority of the NGOs are never completely free to act. They depend on funding, human resources and, frequently, underground connections; they can be submitted to political pressure whether at the national or international level, and sometimes they have to fit in a particular ideology if they want their proposal to get through. In fact, if we except a category of well-established associations having their network of support and a guarantee of a continuous financial flow, most of the others are living and working precariously. They are uncertain as to the possibility of continuing their project, and they thus have no choice but to proceed step by step, on a short-term basis. Such a situation influences their strategy and method of working.

Keeping those considerations in mind, the last session of the workshop, which has received the most attention in terms of proposed papers, will be devoted to identifying various strategies implemented by NGOs in the field of HIV/AIDS in particular, or in the broader context of development which includes HIV/AIDS as one of its components. The purpose here is less to describe the projects in detail than to try to bring out the difficulties found in their implementation, their replicability, to examine together the potential reasons for drawbacks. In fact, what is expected is more a critical and objective assessment than a mere promotion of achievements. We are not gathered to congratulate each other, to prove that we are right and that the neighbour is wrong. We do argue that it is more relevant and fruitful to question the work undertaken and evaluate what the judicious and preferable re-orientations should be, and of course what suggestions should be made, and to which extent these suggestions could be developed at the national level. Finally, the question is raised as to the position of the NGOs in a country like India. What is their influence? Are they bound to be confined to their area and work in isolation? Or are they, all together, capable of rectifying, if needed, the course of national policy?

We cannot expect linear propositions, definitive answers to these questions, but I do hope we will be able to lay foundations and contribute to reflection in that direction. Controversies and polemics are also expected. That is not to say we want a big fight and chaos made of the hall. No, we are just convinced that we have to submit our ideas to others and discuss them together. Polemic means to argue with reflection, after analysis, while personal problems between those present will have no opportunity to be heard during this seminar. I do hope you have come with this feeling in your mind, and once again, I welcome all of you.

NGOs' Involvement in Research and Action

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The idea of the workshop was initially mooted by the Indian Society for Environment with the view to discovering the gaps that exist in the system between the NGOs and government agencies. The realization of this idea has become possible with the National Agency for AIDS Research in France. One of the basic ideas was to generate a forum where NGOs could discuss their doubts, achievements and expectations. Nowadays in India, a great number of NGOs try to approach various sections of the society - specifically the weakest ones-, try to help people who are suffering from HIV and seek a way to resolve their problems by pointing out the discrepancies that exist in the social system. Actually, the Indian point of view is that there are various risks emerging both from our culture and from external influences which favour the outbreak of the HIV/AIDS epidemic in the country.

To counteract those risks, knowledge about AIDS, the proper understanding of AIDS, as well as change in the sexual behaviour have to be promoted. All this can be brought out by means of different strategies of AIDS awareness programmes. The drawback is that presently action projects do not comprise evaluation programmes. How far do the projects succeed in bridging the gaps prevailing in the population and in generating attitudinal changes? In fact, little is known about that. We may be led to error regarding the extent to which knowledge is diffused. People are today still unaware of AIDS in many parts of India, especially in rural areas.

It was in this light that the workshop was planned: what is the course of action of NGOs? In which direction do they have to move? How can they exhibit a coordinated effort along with the government agencies? NGOs may also face many problems in getting financial assistance, in finding logistical support from government agencies. The obvious reason is that government is not in a position to assume a uniform geographical coverage in the different regions, among the different target populations. This particular workshop was also planned to bring out the views of various NGOs as well as to acquire some understanding of their experiences. Experiences from the point of view of awareness programmes and, more importantly, from the difficulties faced. Only by knowing the practical and heterogeneous problems NGOs are facing, can one be in a position to assess what could be innovative suggestions in implementing the programmes, as well as to readjust guidelines in a more adequate way.

NGOs and researchers are now at the crossroads: both of them know after having carried out many awareness programmes and having been in close touch with the local population, that discourse alone is not liable to bring about sustainable behavioural change among people. Immediate behavioural change and long-term behavioural modification are two major processes that are needed today in the absence of any treatment. Getting a clear understanding of the social dimension of the epidemic is therefore crucial for the design of the various aspects of HIV/AIDS prevention and control. In such a context, it is worth while to again emphasize what has already been pointed out: the urgent need to link the social action with research. It implies the involvement of social scientists as well as the acceptance of NGOs and government agencies to integrate research processes and research findings in their development programme. Last but not

least, policy planners should induce a suitable environment to facilitate a more effective acquaintance between social scientists and people in action.

From my experience through the various studies I have carried out and read, I have come to know that people's perceptions and attitudes towards a proper understanding of then spreading of AIDS and modes of transmission, as well as other components of the required knowledge, have not yet been fully evaluated. In this respect, one must consider how NGOs should best take up this missing point, and what else they should do. It means not only creating awareness but also providing better care to the patients living with HIV and AIDs. NGOs may not be in a position to rediscover the socio-economic and cultural analyses which have been undertaken in previous research. Such additional scientific knowledge becomes therefore essential for all the NGOs.

Community care is only taking place slowly because of the high stigma attached to the suffering persons. Food system and alimentation is a potential component of HIV care which deserves to be explored. In India nutritional aspects of HIV infection are to be taken into consideration. The idea is that undernutrition and malnutrition have some influences in the evolution of opportunistic disease and may accelerate the passage from HIV to AIDS. The Indian Society for Environmental Health (ISEH) is investigating that area. We have introduced programmes and carried out studies to discover the traces of nutritive elements in the bodies of infected persons. The purpose is to know whether nutritional components (combined or isolated) influence positively or negatively the infectious state. In other words, the assumption is that some nutritional components may be delaying the progression of the disease in the body. A conference was held partly on this topic in southern France some years ago (1994). Then, a second conference on HIV infection and nutrition therapy was conducted last year in India. A complete lack of knowledge in terms of potential nutritional relationships with disease evolution as to be observed among the NGOs. Further emphasis in the seminar was to increase their awareness of this factor. Sensibilizing the government officials was also crucial. It is essential that suitable programmes on nutritional intervention therapy receive more attention as the number of AIDS case is increasing daily, and because we know that no affordable allopathic drug treatment will be available for everybody in India. The country has therefore to look for alternative and realistic solutions.

NGOs are also conducting systematic awareness programmes in order to explain the epidemiology, the modes of transmission and control and the necessity to modify unsafe sexual behaviour. NGOs give advice regarding how to bring about a change in lifestyles, how to generate behavioural change. But once again, planners and NGOs have failed to evaluate, or failed to collect, the relevance of the information networking system. More research trainers are needed. In India, the heterosexual mode of transmission assumes the higher percentage (80%) among the total modes of infection. Emphasis should be focusing on strategies to modify behaviour and to make acceptable the use of condoms. What is the rate of condom use among commercial sex workers? To which extent do commercial sex workers insist among that clients wear condoms? Numerous studies detect tremendous disparities between the awareness dissemination strategies and the effective acceptance to use condoms. Many other reasons are interconnected: some will argue that they lose their sexual feelings, others that they do not know how to put on a condom, others that it is not something virile, etc. Being closer to the people, the role of the NGOs is more important than that of government agencies: the former have better and easier access, better commitment than the government and bureaucratic agencies.

The governmental institutions try as well to introduce the national programme through the NGOs, which are more flexible bodies and which are supposed to be more knowledgeable

regarding the Indian pattern of health care system prevailing in a particular place. Without the support of the NGOs, a national programme can hardly be successful. But, at the same time, the NGOs should be encouraged to have better access to resources and to the utilization of the funds with a minimum of administrative barriers and control. Of course, the funds allotted should reach the people and a kind of control is needed.

Another aspect is the involvement of the people in the planning process. How do programmes manage to mobilize people? Whenever NGOs implement their programmes, they should first identify the general pattern of the population, then some sub-groups, then some key persons liable to bring out the dynamics of change. These different levels of population identification are still lacking at present in the Indian setting. Identification of leaders among the vulnerable population is required if the developers want the planning to reach the whole population. It may bring about some amount of success, even if not sufficient in itself. Definitely, the responsibility of the people, the responsibility of the community, the responsibility of the NGOs should be clearly defined.

The superposition of private associations should deserve attention. It has become a typical feature in India (specifically in Tamil Nadu) that whenever two or more NGOs act in a particular area, they cross each other, introduce similar programmes without consulting each other and without bothering about the confusion which may be created among the targeted people. Such a situation is exacerbated by the different nature of the messages they provide according to their heterogeneous ideologies: one NGO is providing awareness by promoting condoms while the other does not talk about this method of prevention. Conversely, sharing the same geographical regions and targeting different groups (through various NGOs) may yield good results if the organizations work in synergy rather than simply repeating programmes, or acting in contradiction.

For this purpose, NGOs should have national and local networks which would enable them to identify the geographical regions, the areas of research undertaken in a given place. India being the second most populated country in the world, it is very difficult, if not impossible, to conduct any national programme which reaches the entire population. The number of NGOs is increasing drastically, but if we have in mind the number of NGOs in relation to the total population of the country, the number is insignificant. In some states like Bihar, NGOs are virtually absent, also in the field of HIV/AIDS. Even in some remote parts of Tamil cities, there are no NGOs actively present. The spatial distribution of NGOs is not balanced. The geographical disparity dimension must be taken into account: national agencies should favour the implementation of NGOs in new areas. Given the prevailing condition, the establishing of a network among NGOs is essential. Perhaps the workshop will come up with innovative findings and conclusions regarding such networking aspects. In that case, a notice could be passed to the government as well as to the policy planners in order to induce a protocol of proper articulation between the NGOs and the governmental agencies.

Discussions

Usha Raghavan : It is quite interesting to talk about the networking and the spatial distribution of NGOs in particular geographical areas. But, having experience with NGOs for the past 5 years at the Tamilnadu State Aids Control Society¹, I observe that networking is still a project in India, and that Tamilnadu is ironically supposed to be a model for the other states in the country. At the grass root level nothing is done. I would say that networking is the major drawback among the NGOs. I don't know the reason behind this. It must be a combination of competition, suspicion, struggle for prestige. Every day there are new NGOs emerging or trying to establish themselves. According to their requirements, there is not place for everybody, at least in terms of finance availability. Another criticism is that most of the NGOs absolutely avoid the research dimension. This being the case, without having even a basic knowledge of people's day-to-day life, how can they implement any proper project? The importance of social science research is known to the social scientists but insufficiently to the non-specialists. Until NGOs undertake some baseline survey, they cannot identify where the sex workers are, where the target area is going to be, in which field they have to concentrate. I am not blaming the NGOs involved in the area of HIV/AIDS. The sad fact is that there is no provision at all for the research. Donors do not encourage the research aspect. They expect targets and achievements and want the NGOs to provide clear reports which show an increasing number of condoms distributed, and so on. On the other side, the scientific medical research is given priority. It is legitimate to try to discover a new medicine or vaccine. But even if that were to be successful, social research cannot be avoided. In terms of prevention, if there is no behaviour modification, the situation will get epidemiologically worse and worse. That is why baseline surveys have to be given importance by the international agencies as well as by the government.

Prof.Gurumurthy : I am an anthropologist from Dharward University in Karnataka. I disagree with Usha Raghavan because the NGOs have to do certain type of work. It is the job of the social scientists to conduct the research and then to keep the findings ready and available. Social scientists have to work no doubt in collaboration, but if the NGOs begin concentrating on the research aspect, it may be difficult for them because there are few people, meagre funds and little time to cover all this set of activities. The solution would be that NGOs should work hand-in-hand with social science agencies. The combination would generate a synergy liable to improve the action-oriented work.

Usha Raghavan : That is what I mean. I didn't say only NGOs should take up the research. When they want to realize baseline survey, the funding agencies should appoint the research agency for a collaboration. I am not saying NGOs can do it alone. NGOs are not in a position to take up the research because the time allotted to them is also limited and they do not have the provision for employing a social scientist. In Tamilnadu, the funding agencies which are to pass via the government, or more precisely a semi-government apex (TNSAC), have to take the responsibility and to make available some provision for the development of social science research. International agendas must proceed in that way. So it is not the NGOs fault.

Prof. Gurumurthy : It is presumed that NGOs will start to implement their projects only after knowing what the problem is, where the problem lies, and how to deal with it. Unless they are in possession of a minimum of tools and knowledge, for instance the meaning of the social, I do not think that NGOs will rush to do something by themselves.

K. Santosh : While implementing the National AIDS Control Programme, the government of India have given no importance to social scientists. No creation of social scientific posts for the programme has been enjoined. Consequently, Indian deciders have left aside the social aspect of the epidemic. It is a pity because the country could have benefited from the experiences in Africa and in Europe. But this has not been the case at all. Similar errors have been made, I would say, knowingly. The social dimension was perceived as something of secondary importance. They have given priority to medical and technical personel. For that reason, what Usha Raghavan said is correct but insufficient. It is a structural problem. The biomedical establishment deliberately tries to manage the epidemic. There is no scarcity of social scientists : they are not supposed to be a part of the people involved in the struggle against HIV/AIDS.

Prof. Gurumurthy : There are national level research agencies like the Indian Council of Social Science (ICSSR) and many other university research centres. then there are a lot of independant research centres like the ICLAC. Each one of them is doing a lot of work on HIV/AIDS. But there is neither coordination nor cooperation between the agencies themselves. Worst, there is poor collaboration with administrators and people in action. Everybody is still working as a different, autonomous and isolated entity.

K. Santosh : Maybe. But regarding the case of the funding constraints outlined by Usha Raghavan, the international agencies and to a lesser extent the local governments (i.e. state) are nowadays the main sources of income for the NGOs. Because of the externalisation of the funding, local

¹ The official semi-private body in charge of the prevention programmes in Tamil Nadu.

Universities are poorly encouraged to establish some durable networks with NGOs. Unlike NGOs, universities - for some administrative, logistical and legal reasons - are in a difficult position to receive funds from the World Bank, the European Community, the United Nations and any outsiders. Paradoxically, the research is separated from its original place, where it is supposed to be taught. It generates opportunity for private-oriented marketing research centres to endorse the research activities. The question is whether it is advisable to associate business with research activities.

F. Bourdier : To sum up schematically, we may say that the private sector receives, but not exclusively, much more material support than the public sector, including universities and other government research institutions. Institutional research bodies, except a few like the Tata Institute of Social Science in Mumbai (a private body sponsored by the Tata group), are poorly encouraged by donors to improve their skills by receiving, for instance, an additional teaching curriculum, scholarships for PhD students, and money packages to launch research programmes. On the one side, foreign agencies are reluctant to face the Indian administration which systematically entails time delay, money retrocession and, worst of all for some international donors which are a part of the globalization process, potential control by the Indian Government over their activity. On the other side, human resources are under-utilized or, more precisely, selectively utilized, because priority is given to private persons irrespective of their background. Some of these private persons benefit the system because they have been able to establish underground social networks, political ties, economic acquaintances, friendships, if not allegiance, clientelism. In Chennai for instance, there are NGOs run by influential politicians and their relatives, by retired Indian Administrative Officers (IAS). Such groups of people know how to get money either from abroad or from within the country. They are empowered to get both public and private money. Personal motivation and research capacities are merely secondary factors for their involvement. It creates a gap between academic research undertaken in colleges, government institutions and people who become - sometimes artificially, sometimes because of opportunity - involved in research action and who are not necessarily in possession of sufficient tools and knowledge from a given social discipline. Frustration turning to jealousy is a direct consequence of unequal distributions of assets. The purpose should be not to favour either one or the other sector, but to mobilize and utilize all the available human resources.

Prof. Gurumurthy : I realize that we have come back, with detailed clarifications, to what I suggested earlier. That is, that the NGOs should get together, interact and present the problems that they face to social scientists. NGOs are in constant and close contact with the population. It allows them to have pragmatic experience of the quality of interaction occurring within the community. Scientists can orient them, provide methodological issues and new ideas. I do hope these points will be adequately recognized and discussed in the coming days.

S. Surender : I belong to the International Institute of Population Studies (IIPS) in Mumbai. We are academicians but we have experience in collaborating with NGOs. The basic problem with the NGOs/social scientist relation is that we, social scientists, are not able to identify the evaluation at the outset. To start with, most of the intervention programmes are accepted for evaluation after the intervention. Evaluation is not thought about in the initial stage. Once the intervention is finally over, the developers engage researchers like us. No baseline survey data is available. So we have to come up with some findings, depending upon which funding agency has asked for our services at a given time. Most probably, the hidden agenda is that we cannot say no to an intervention which is providing ultimately an unsolved problem. Nor are we in a position to decide when the evaluation should be undertaken. In our view, it should be thought of at the beginning of the intervention stage itself. Evaluation done only at the conclusion of the intervention may not be useful for further research.

A. Shanmunganandam : I do not agree. The evaluation process can be carried out after implementation. Some modifications can be done when we plan for the future implementation. Once NGOs have conducted their awareness programmes, the discrepancies can be easily found out. With ISEH for instance, after the presentation of the awareness programme, we would conduct pre-evaluation and post-evaluation tests in order to know what amount of knowledge is available for an individual who is potentially exposed to AIDS information. After carrying out the awareness programmes, we undertake a post-evaluation. This is where we must find out who are the people and who are the groups that are not able to receive the information and to detect the points which are misunderstood. It may involve many instructions regarding the regional languages and social conditions of the people. Sometimes many diagrams, figures, videos, movies, slides used as visual explanation for the people have to be changed. It is important to know this in the sense that at present people get a lot of awareness messages because of the increasing development of audio-visual techniques related to AIDS. But audio alone cannot help people, because they sometimes just listen. It may be just to pass the time, like going to the cinema. It does not mean that they understand and will behave consequently. This is why we have carried out studies in Madurai City in order to learn about the feed-back to our programme interventions.

F. Bourdier : Superficial analysis leads only to superficial statements. I do agree that it is important, legitimate and necessary to know what the people know and think about AIDS, sexually transmitted diseases, reproductive health and so on. But it is far from sufficient. The pre-evaluation

and post-evaluation assessments you are talking about are based on individual statements influenced by psychologists' theories. Numerous studies all over the world have definitely proved that one cannot change individual behaviour without taking into account the sociocultural, and politico-economic conditions which give birth to them. Behavioural studies based on a mechanical perception of human decision do not provide a clear picture of the social reality that individuals and groups are perceiving. The second critical point is that even if one is aware of the danger of the epidemic, it does not mean that one will behave in a rational way in order to avoid this danger. In other words, there is no direct correlation between knowledge and behaviour. The third point is that rather than blaming the people of having misconceptions, false reasonings and a poor ability to understand, it would be more judicious to have a clear understanding of the socio-economical and cultural dynamics in which they are involved and which may act as constraints, and therefore to try understand their world through their own categories of thinking.

Child Abuse and Prostitution in Tamil Nadu

Mrs. S. Usha, Women AIDS Action Development Society, Trichy (Tamil Nadu) Representative for the National Committee for Women in India

Indian society is composed of more than nine hundred million people. Since the outbreak of the epidemic, the so-called commercial sex workers have been the scapegoats and are accused of being responsible for the growth of the epidemic, to be the vector of the virus. It is a facile statement which prevents the rest of society from being accused, if we except a few other targeted groups such as truck drivers and homosexuals.

In reality, if some women in prostitution are infected, and it is a matter of fact, one has to remember that they did not get the virus from the sky. Men gave it to them. It could have been a Minister, or a rich industrialist, a respectable father from a typical middle-class family, a mill worker, a land-owner, a rickshaw driver.

The men come to see a prostitute by choice; the women receive them most of the time by constraint. The former did not bring condoms with them, and if it was proposed by the women, men have refused in many cases.

When speaking about the question of prostitution, NGOs, government and social workers have to consider different contexts. It is also surprising that while women in prostitution are in a situation of vulnerability and consequently are the first persons in danger, they are considered dangerous by society and are, therefore, also neglected.

An illustration of this social and individual vulnerability to HIV/AIDS may be given by focusing on children entering into prostitution.

There are about 400,000 to 500,000 child prostitutes (boys and girls) in India, according to a survey done by *India Today* magazine. Research suggests that such exploitation is growing, and that the age of children involved is falling.

Most children in the sex industry are girls between 13 and 18 years. Many such children spend most of their lives on the street, often because they are escaping violence or sexual abuse at home. Other children live in brothels, having been brought into them by procurers.

The physical and mental abuse of children may increase the likelihood of their engaging in risk-taking sexual behaviour and thus increase their vulnerability to HIV.

The HIV/AIDS epidemic has made child sexual abuse and abuse of children within prostitution more dangerous than ever before.

Studies everywhere indicate that rates of HIV infection among children involved in the sex trade and street children are often very high.

The belief that children are less likely to be infected has raised the demand for younger sex workers in recent years. The vulnerability of children to sexual exploitation, either through sex work or abuse, may well result in their becoming infected with other sexually transmitted diseases such as gonorrhoea, syphilis and chancroid. By damaging the surfaces of the reproductive tract, physical trauma and sexually transmitted disease each increase the child's susceptibility to HIV, as well as the risk to their clients.

The National Commission for Women is taking steps to tackle the problem of child abuse and prostitution, insofar as it has not been debated and taken practically into consideration. The National Commission for Women recognizes that community organizations of women in prostitution can be the most effective agents towards combating the abuse of children within prostitution.

First it undertook comprehensive research to have a clear picture of the sociocultural situation. Through our own investigations with over 200 women in Tamil Nadu, several of whom have been working in prostitution from a very young age, the National Commission is in a position to point out some facts which NGOs, government agencies, activists and planners sometimes ignore.

It is a myth that poverty alone is the reason for children entering prostitution. The absence of "safe" and "secure" relationships within the family/community which sustain the turbulent passage through adolescence, compounded by poverty, lack of marketable skills for gainful employment and rising aspirations, fuelled by a rampantly consumerist society, are increasingly encouraging children to leave their homes.

Most young women entering prostitution are from rural areas. They come from interior villages surrounding main cities and towns.

It is a myth that education is the key to this problem. A significant proportion of the minor girls met had studied up to the secondary level. However, they had no skills that would get them a job.

It is a myth that all families are loving and caring and that parents automatically take responsibility for the children they bear.

A surprisingly high number of girl children are sexually abused within the family. This often forces them to leave home and seek shelters that do not exist. Instead, they get drawn into the vortex that is prostitution.

It is a myth that society and its welfare structures really care about the child abused within prostitution. Till today, no structures exist that can care for her emotional and physical well-being and rehabilitation.

It is a myth that all children are equal in the eyes of the law and have the same rights.

While activists clamour about the sexual abuse of children outside prostitution, not a whimper is heard regarding the continuous rape of children within prostitution. Instead, society and law enforcers go so far as to label them offenders under the law.

Despite the so-called "efforts" of a "concerned" police system, there was a 60 per cent increase in the number of rapes of girl children and a 100 per cent increase in the numbers involved in prostitution between 1990-94.

The National Commission for Women recognizes that these myths have to be directly confronted before specific courses of action can be considered.

The National Commission for Women experiences the life of women and children in prostitution as a reflection of the continuum of societal oppression and bias against girl children and women in general.

However, the physical and sexual abuse of children is experienced in its most extreme form within prostitution, through the confinement and rape of girls and young women.

The National Commission for Women further recognizes the vulnerability of the girls/ young women in the context of rapidly rising rates of HIV infection. It wishes to place this concern firmly in the context of any discussion regarding the abuse of children.

The National Commission for Women affirms all the resolutions adopted by the UN declaration on the rights of the child; in particular, that the State shall protect children from physical or mental harm and neglect, including sexual abuse or exploitation.

The National Commission for Women commits itself to facilitating effective implementation of these rights and recommends that these be anchored firmly in all development plans and policies of the country.

The National Commission for Women recognizes the need for enlightened and socially relevant legal rectification of the prevention of physical and sexual abuse and rape of children for a lasting solution.

It recognizes the need for concerted efforts by NGOs, community-based organizations, governments and other agencies towards this end. This concerted effort is absent at present. And we are wondering why the law is not respected, why NGOs are not approaching this problem directly, why there is no attempt to focus on the family context (which seems to be the key to understanding), why women in prostitution are targeted and not perceived as victims.

The National Commission for Women recognizes the role and value of the collectivization of women in prostitution as an important step towards dealing with the issue of confinement and rape of girl children.

Finally, the National Commission for Women pledges to effectively and realistically address the well-being of these children and commits itself to the political will necessary to create a better environment for all the children of our nation. Institutional and government responses are very low, if not absent or ill-oriented.

No institution has any programmes specifically aimed at preventing the sexual abuse of girl children and their entry into prostitution.

No specific effort is made to verify the ages of the girl children, and if arrested and sentenced to remand, they are all detained in the government vigilance homes along with adult women.

No specific effort is being made to reach girl children within prostitution, either for their education, rescue or rehabilitation.

No attempt is made by any agency to specifically focus on girl children, their shelter, education, vocational training, counselling, etc.

No institution is actively concerned about preventing the entry of girl children into prostitution. Instead, all efforts are aimed at rescue and rehabilitation, even though they are not specifically focused upon children and are directed towards women in general.

There are no counselling activities, with adequate resource persons, available for victims of sexual abuse anywhere in the State.

Consequently, there is an urgent need to take all these points into consideration, as well as to change the preconceived ideas which are rampant in both NGOs and government implementation projects.

Discussions

Dr. Abdoul Amide : You have presented an unusual paper and a few points deserve to be clarified. One of the factors which has led to people - either children, women or men - being driven into prostitution is their lack of marketable skills. This is a point which NGOs can take up. Among the people involved in prostitution, they could impart to those who are liable to be rescued some marketable skills. Take the example of leprosy. There was a social stigma attached to the disease. A long time back, an institution was created in Pondicherry where people were taught skills like making baskets and handmade paper, printing and binding. How many of the commercial sex workers will be willing to learn a new skill, and to which extent can this skill satisfy them in terms of money opportunity and interest: these are questions that you have raised, with misgiving, in your paper. Since we are always talking about awareness and the use of condoms, we should somehow concentrate on the roots of the problem: how to divert them from the profession? NGOs should have a more integrated approach and should be in touch with some other NGOs working in the development field. Job empowerment is essential. Because one may presume that people in prostitution are neither involved by choice nor because it provides job satisfaction. How many of them will be willing to give up prostitution if offered an alternative employment? Social scientist should think about this.

F. Bourdier : As social scientists we are not supposed to make any judgement about anybody. As you say, those willing to be rehabilitated may be encouraged, and one has to undergo the feasibility and the acceptability of a sustainable rehabilitation. But how and under which conditions? Frequently, rehabilitation programmes in Tamil Nadu are hardly acceptable for the women. One has to see what it is going on in the government vigilance homes and in the rescue homes which are supposed to generate new inclinations, to provide a new social environment. In fact they are functioning as mere jails. Discrimination and disdain are common features. Worse, it happens that some brokers (i.e. people who act as intercessors and who engage the others in organized prostitution) use the centres to identify new attractive and vulnerable women. Further more, in the so-called rehabilitation programmes the women are taught old fashioned skills like thread making and puppet decorating. One cannot call those activities "skills". Consequently, most of the women try their best to avoid such a static situation and manage to run away as soon as they can. On the contrary, women should have the possibility to decide what skill is going to be helpful for them in the future. In that respect, researchers may look into the acceptability and the feasibility of such social projects by designing a social cartography of the constraints and choices faced by the persons.

Carlos Sequeira : I am from Freedom Foundation. In Bangalore we are in touch with destitute women and most of them come voluntarily to our centre. Those who are HIV positive may use our facilities and we do our best to take care of these women by providing psychological support, food, shelter, basic cure for minor ailments. Most of the time, these women are alone in life. We intercede with the government and public services. But

from the government side, building capacity resources are not taken into consideration. Many times I have been to the office of the Karnataka director in order to ask her to take the responsibility for those that we are not able to keep, either for severe medical reasons, lack of place or insufficient money. The lady officer used to refuse to send the girls who are HIV positive to any public institution. The director usually calls the families of the seropositive children or seropositive women and tries to convince the relatives to take care of their daughters, without telling them about their seropositivity. What happens is that most of the girls are terrified to go back to their families. One of the main reasons is that these girls once have been sold by their own parents and if they come back, they are afraid to be sold again. Administrators have absolutely no idea of what is going to happen to the girls that they try to rescue without having conducted proper inquiries into their family environment. The second fact is that they do not know how to deal with HIV-positive people. Maybe because there are no legal provisions, or simply because they are unconsciously discriminating against the infected persons. Then, quite a number of orphaned girls are still locked up just because they are HIV positive. Not because they have done something wrong: just because they have been tested positive, mostly through mandatory testing. Our association is looking up the various ways to pressure the government to release these girls. Freedom Foundation is an organization which is more and more focusing on the rights of positive people and of child prostitutes. Definitely, a close relation with S.Usha and the National Committee for Women may stimulate new insights.

Prof. Gurumurthy : Your assessment has to be commented upon. Mr Sequeira first mentioned that child prostitutes were sold by their parents. I would like to know how for sure he can assess if they have effectively been sold by their father or mother. It is not a particular theory, but no parent from my experiences with devadasi-s (i.e. god prostitutes) would do this. Neither parent nor kinship by blood will do this. The family may be cheated. In that case, without their knowledge their girls may be sent to brothels. The family will be assured that their daughter will get a god and lucrative job. The only situation in which it may occur is when there are adoptions. In some families, children are given, exchanged, sold and taken from the family. In that case, if somebody claims a few years after "this is your child, come and take her", it will not have any effect.

Dr Venkatesvaralou : I would like to make another clarification. Mr Sequeira mentioned that parents sold their children who then are turned into forced prostitution. The abandoned or kidnapped children were taken from the family; but afterwards these children can get financial help from the person who employs them or bought them. I don't think you do have figures and facts to verify and to prove such statements.

Prof. Gurumurthy : Let us go back to Mrs Usha's paper. Mrs Usha was just mentioning that women in prostitution were not having a skill, a commercially viable skill. Let me draw attention to the fact that in the Indian caste society, each caste has its own traditional occupation. Today in rural areas some of these occupations are lost, like the basket makers, the pot makers and many other crafts. Villages have lost their weavers, because in the city the factories provide cheap durable aluminium vessels that are available and affordable to everybody. Nobody bothers to buy pots except for decorative purposes. It is the same with the basket makers and with the weavers and leather workers. So NGOs want to give the so called destitute ladies some skill, only after they have become prostitutes. It can be too late. Ex-prostitutes usually are haunted to be brought into some institutions. As an anthropologist, I am sensitive to what is known as culturally and psychologically compatible in that domain. If I want to give work to somebody, the work issued should be logically and culturally adapted. For example, if I ask landless low-caste labourers to keep a cow and then to sell milk, they will not do that because socially and culturally they are not accustomed to doing that; instead, if you ask them to keep poultry, they may accept and do well. Reciprocally, upper-caste people may not keep poultry as far as they are vegetarian and, consequently, are not psychologically prepared to rearing chickens or any type of domestic animals. NGOs have to take into consideration what we anthropologists call "culture". Unless developers look for what can be culturally compatible, the people will not accept what will be perceived as a constraint for them.

Dr S. Subramaniam : Congratulations Mrs Usha on your presentation. I happen to belong to another NGO that deals with girls caught, sentenced and released under the Immoral Traffic Act (ITA). My organization takes care of these ladies who have been abused either by their family, husband, friends or peers. The staff members take them and train them in rehabilitation skills. We have had some measure of success in getting some of them back to their husbands and back to their homes without lasting conflict. At the present moment, the strength is about seventy and there are four children in this group born of these girls. ISEH conducted a survey regarding their HIV status. We found that four out of them were HIV positive. It is a lot, but at the same time we were happy about the result because we feared it would have been much more.

G. Gunavathy : Regarding what Sequeira said, not only in Bangalore, also in Tamil Nadu, ladies were rescued from brothels. After one year a survey was undertaken by some Tamil magazines about their present status. They found that again most of the ladies have disappeared and /or gone

back to their old profession. The problem is that the attitude of society has not changed. To provide them with a new life is not sufficient. Society has to accept them, or at least to forget the past. But this never happens. Even if you ask some people to keep an abused woman as a housemaid, there are chances that they will not accept, because of the stigma, and because of the potential influence she may have on children, etc. In fact, society cannot help itself from being afraid of her. The attitude of society is such that situations of vulnerability have poor chances to be modified, whatever NGOs or the government have done to rescue them. I don't know how far rehabilitation is going to be helpful on a long-term basis. The second aspect which was pointed out by Mrs Usha was that sexual exploitation within the family is high in Tamil Nadu. Compared to other states in India, random surveys by the National Family Health survey show that 50% of the marriages in Tamil Nadu take place within the circle of relatives. This is a very specific pattern of Dravidian kinship which explains the very high rate of cross-cousin marriage and maternal uncle/niece alliance in Tamil Nadu. Sexual abuses within the family are frequently reported: the potential traditional right to marry one's female cross-cousin for instance, allows men to take advantage of this prerogative. It is a major fact in Tamil Nadu and we hardly speak about this. We cannot easily tackle the problem of getting married within the circle of relatives because it has certain advantages in terms of dowry, land inheritance, property rights, social acceptability. But the age at marriage among the girls who get married with a close relative is generally very low. Biological disadvantages are very high and this social situation increases individual vulnerability. It happens that many girls cannot bear this situation, and one of the extreme solutions is to runaway which, conversly, makes them vulnerable to being driven into prostitution. Available figures tend to demonstrate that sexual exploitation within the family is higher in Tamil Nadu than in any other state; but in Bihar and Uttar Pradesh I have been told that various kinds of incest - that is between parallel cousins or between persons from the same gotra (clan) - frequently occur. It is a very sensitive issue in a country like India because the family is idealized. However, the problem finds its roots in the family system which is no longer adequate to the contemporary way of living. y words are just an example to show that superficial approaches will cure the symptoms but not the disease.

Male respondent : Why has S.Usha, who is a member of a women's committee, stated that men infect women. Cannot it be the contrary?

S. Usha : I will not accept that. As far as AIDS is concerned, men pass it on to women. Please bear that in mind. We live in a patriarchal society where man alone makes decisions in sexual affairs.

Male respondent : But from where did men get HIV/AIDS then?

S. Usha : Homosexuals, why not?

Dr. Venkatesvaralou : Another pitible dimension is the poor innocent housewife who has not committed any crime, except being with her husband who had himself been infected by somebody else.

F. Bourdier : You speak about "innocent" women. This means that there are other women who are not innocent. If we start to wonder whether this one is a victim or that one a culprit, we are going to judge the whole society which is meaningless and goes against any prevention efforts. Morality has no place when dealing wiyh care. Regarding the epidemic, everyone has to be considered as a victim. What is the use, in terms of individual and collective prevention, of making this artificial distinction? One has to remember that discrimination starts at that level whenever a society tries to find scapegoats. It is recognized that such discrimination will in turn mitigate the preventive measures undertaken by NGOs. If someone has a car accident, the witnesses will call for an ambulance: there will be no question of inquiring before whether the injured persons were driving carefully or not. In the same way, when dealing with HIV/AIDS, everybody has the right to receive affection and to be rescued. Every accusation is a social reappropriation, insofar as some social groups may have an interest in accusing others. Not only in terms of social justice and ethics but in terms of personal and civic responsibility, we have to be aware of the permanent danger that gives way to voluntary or involuntary stigmatization.

Dr V. Jeysingh : From my experience of working with the sex workers in Belgaum and Dharward in Karnataka, I have been stuck that most of the time the same person is arrested and released. We know that in Karnataka, every week (Friday) policemen are supposed to book a certain number of cases. Ladies in prostitution are aware of this, and feel safer staying at home on that particular day. If one is a poor cycle rickshaw man without light on his vehicle, the policeman will catch him, because he has to book a certain number of cases per week. In the same way, the police will go to the brothel and say to brothel keepers "Give me three names". Usually in the brothels, the owner will give three names of girls who are either

menstruating, not keeping well or are affected by a sexually transmitted disease. Afterwards, at government expense, the girls who are caught will be removed from the brothel and put in a state home for women. They will be kept there from three to six days and then released. Some prostitutes are treated like this regularly. You can easily imagine the psychological state of mind they develop. I don't know whether they are given any medical care and to what extent the overpopulation is the cause of any absence of legal procedures, before the judge pronounces any judgment. The magistrate will ask the jailer or the person in charge of the state home for women, "Do you have space for four more women? (...) because I am sending other persons". If the answer is negative, the judge will immediately charge a symbolic fine and release them. There are many discriminating factors responsible for the social vulnerability of the ladies.

David Thiagarajan : I am from IMAGE, a NGO based in Madurai. One can observe a similar process in this city in Tamil Nadu. Sometimes, there are some "professional" ladies who have a commitment to both the local police and the brothel owners. They accept, against a reasonable tip, to be officially taken to the police station where a file will be opened. In fact, they believe that there will be no long-term implications because they will be freed just after their deposition. Then they will probably be voluntarily taken again a few weeks later. There will be a rotation between girls who are part of the game. It would be an error to perceive police, brothel owners, pimps, brokers and girls as different entities. It is like a kinship with its own network, affiliation and shared benefits. Although, the ladies are of course more victimized.

K. Santosh : Mrs S. Usha was very particular about the designation: What should ladies who sell their bodies be called? From my past experience while working with various NGOs before shifting to research, the women were referred to as commercial sex workers because they sell their body for money. If we follow this logic, every one is selling his or her profession for money. A doctor sells his medical advice for money; a lawyer sells his knowledge of law in the same way. But nobody says that a doctor is selling a treatment. Why then we denote only the sex workers as *commercial* sex workers? They have only their body to earn a livelihood. So they sell. Usha and her fellows objected at the National Commission to the use of the term CSW because it is full of ambiguity. We rather say "women in prostitution", mainly because most of the ladies are not only working as prostitutes, and because it is not a choice. Some have a respected permanent job, others are housewives, others are only occasionally involved in the sex trade. The fact is that in Tamil Nadu women themselves reject the terms prostitute and CSW.

Ramkumar : I am a student in psychology, coordinator and field worker for a NGO in Pondicherry. The terminology of prostitution has changed into commercial sex work. Let it be. But if the Indian Commission on Women's Right (ICWR) recommended another change, it has been rejected by the government. The word prostitution seems to carry a stigma. The ICWR makes the designation " women into prostitution " a more dignified term than the word prostitute. Nowadays, the latter is internationally accepted and all journals employ mostly the term commercial sex workers. It is confusing and a waste of time. I don't think ICWR is competent to lobby for changing things like that. We may wonder whether the concerned ladies think the word prostitution is more respectable than commercial sex workers. But personally, I fully disagree with this. I would like as well to tell you something that happened in Pondicherry. A good looking girl was in the profession for about three to four years. A policeman along with another home guard happened to meet her regularly. This happened four or five times. Both of them had sex with her. One day she was arrested by the same policeman. Then after a mandatory testing, she came to know she was HIV positive. She was cast off by the brothel she was attached to, rejected by her fellows and by everybody who knew her. Then, she thought of voluntarily infecting men, specially the policeman who used to force her without using a condom. She wanted a sort of psychological revenge : "Society has given to me, I have to give back". This sad anecdote is not isolated. It has also happened in other places.

G. Geetha : What did you do afterwards ?

Ramkumar : Our association not only counselled her, but advised her that ultimately she will not earn any lasting satisfaction out of her primary reaction, that the customers who come to her afterwards are not involved in her past story.

Prof. Gurumurthy : Speaking about prostitution, a clear distinction should be traced out: the common prostitutes and the sacred prostitutes, also called devadasi-s. You have to differentiate between these two categories because the context and the implication differ. In some countries, prostitution is legalized and licenses are given. In those countries, when we use a particular word, it gives a different meaning in terms of acceptance, law and - to some extent - integration. Then you have to explain what you mean when using the word commercial sex worker in a particular context.

The problem with India is that no licenses are allotted to ladies in prostitution in spite of a few social movements which emerge sporadically in Calcutta.

F. Bourdier : In fact, the need for an alternative designation has been decided by the representatives of the women in prostitution. They had named themselves as women in prostitution. Who are we to decide on their part the relevance of this or that? They have decided. They have a National Commission for Women which ratified it, that is all. They fight for their fellows and they have the right and the duty to do that. That is what S. Usha tried to explain to us. As Prof. Gurumurthy said, situations may change in India. But we cannot interpret the recent and ongoing movements as minor events. For instance, Durbar Mahila Samanwaya Committee is a forum of 30 000 sex workers from different red-light areas in West Bengal. The organization has a strong network among sex workers and is fighting against injustice, exploitation, oppression and for solutions to their day-to-day problems. In November 1997 (a few days after our seminar), they are organizing a National Conference on sex workers at Calcutta. The central theme of the programme is about workers' rights. Inspired by the success of their action, they are organizing in March 1998 another meeting. But on a regular basis, they struggle against the precariousness of their life and try their best to make a cross-section of people aware of their problems and disseminate their issues to people in general: they are conducting opinion polls on workers' rights for sex workers throughout Bengal, street cornerings, organizing interactive sessions with political parties, trade unions, NGOs, women's organizations, intellectuals and media. One of their aims is the legal recognition of the sex trade as an occupation, the existence of a self-regulatory board, a demand for worker's rights, the prevention of entry of minor girls into the profession and human rights.

S. Usha : Being a representative of the Women's Organization, I can explain why we choose to call our sisters "women in prostitution". It means women who have been forced into prostitution, or women who have been cheated. If you say commercial sex worker, implicitly there is a choice that the woman wants of her own to be a commercial person selling her sex. "Women in prostitution" does not have this social connotation.

Dr. Venkatesvarelou : I just want to know if there is any NGO controlling prostitution? Because prostitution is controlling this epidemic.

Prof. Hema Devaraj : What is the role of NGOs in controlling prostitution? I am working at Madurai government Rajaji Hospital as a professor and doctor. We used to see them in my service, which is the sexually transmitted diseases ward. The magnitude of commercial sex workers in and around Madurai city has been pointed out, but concretely what are NGOs doing? What are their positions?

David Thiagarajan : Image in Madurai, Community Action Network (CAN) launched by K. Pradeep and South Indian Action Programme (SIAAP) launched by Shyamala Nataraj in Chennai were three of the first NGOs to concentrate their efforts on prostitution. I will speak about Image very briefly. We have an integrated approach so that we intervene not only with the ladies involved in prostitution but with their husbands, the rowdies (local mafia), the procurers, the pimps, the brokers, the middle men, the policemen, the money lenders, the clients and so on. Our philosophy is that if we try to change the women's behaviour without having the support of their surrounding environment, efforts will be meaningless. In Tamil Nadu, we can hardly speak about women's empowerment if we do not interact as well with the other persons liable to mitigate this empowerment. Ultimately, the objective is to generalize and banalize the use of condoms, which is interpersonal matter when it comes to the point. But basically, sexual negotiation is undoubtedly a social matter. I have to say that we are not fighting systematically against prostitution, even if whenever it is possible we try, with the help of other NGOs dealing with social welfare and development purposes (protestants, caritative organizations), to rescue some of them. The problem is that we have limited material capacities. We just try to make prostitution safer in terms of women's health and social justice.

Dr S. Subramaniam : You said that you are distributing condoms to the commercial sex workers. What type of negotiations are possible and thinkable between the clients and the CSWs ? How can the situation be improved? If you clarify these points, it will be useful for the participants of the workshop.

S. Usha : I am ready to give ideas. I have done so before other participants at other workshops. If it would really be useful as you suggest, I am ready. I am afraid we are just producing abstract ideas without debating under which conditions programmes can be implemented. Implementation is 90% of the work, ideas represents only 10%.

S. Surender : Mrs Usha, though you would have spoken on sensitive issues at many conferences, we have not attended them. We ask you just to share your experience. It will be useful to us. Is the use of condoms always opposed by clients or by the commercial sex workers? There may be some who may not like to use condoms. On the other hand, child abuse and sex bonded labour are sensitive points that the government has so far not been able to solve. One may imagine that the government would prefer to hide the facts, to get rid of an embarrassing problem. But now media, NGOs, social scientists speak openly. At least, from the workshop point of you, we can discuss these matters. You have stated in your paper that the clients refuse to use condoms. The women are put under various constraints and they are forced have sex without the use of condoms. Several years ago when I was a member of the Population Control Organization, there were also people who absolutely refused to use condoms. At that time the problems expressed by the voluntary workers were different. Even the couples refused to use condoms during the fecundity period. Psychological reasons, intimacy reasons, virility reasons, and so many other possible explanations. With the advent of AIDS, when the question of life and death is involved, still the people are refusing to employ them. It is another dimension. That is why I am interested to know what type of experiences you have had or what type of comprehension you faced in this area.

Dr S. Subramaniam : Many studies have come up with detailed analyses of the reasons for not using contraceptives. Especially regarding condoms, it has been reported in rural areas that whenever the health worker is a female, the man cannot go and ask for a condom. The village folk will also not send their wives. The couple feel rather to go to the shop. But then comes the problem of availability. Condoms are not for sale in villages, but are only available in cities. I wonder whether similar problems of availability are faced by the commercial sex workers.

Ramkumar : We are working with the commercial sex workers in a small brothel based-area in Pondicherry. We are counselling the sex workers in jail as well. Through our focus group discussions that we had in the prison itself, we came to know that their knowledge was very high. But as far as the condom is considered, it is not used with clients. One reason is the non-availability of condoms at the site. In rural areas, it is not available because if you buy everybody will know. Secondly, the clients are not interested. According to the clients from the STD clinic we have interviewed, the clients are not satisfied with the condom. There is a question of quality, but not only. For example, a fifty-six year old man told me that using a condom is like taking a bath while wearing a rain coat. The sex workers are paid more for accepting unprotected sex, with or without the consent of the aunty (i.e. woman in charge of the brothel). Now if we consider occasional sex workers who are family housewives, there is a much lower perception of risk. Condoms are hardly used. What I want to stress is that in the brothel-based areas - not only in Pondy but in Mumbai, Calcutta - permanent sex workers are more insistent on the use of condoms. They are more willing and more in position to do so because, being together, they are empowered. In jail, we had discussions about sex-exploitation with the ladies also. Many of the sex workers have undergone stress and strain because of rape, forced group sex with three to ten men. It happens mainly with the rowdies, as well as with some "official groups" whose government affiliations I prefer not to mention in the seminar. Women said that during these collective assaults men hardly use condoms: if one starts without, the others will imitate him.

G. Geetha : There are a lot of beliefs linked with the perception of sexuality and body fluids. During the intercourse some of the clients tear the tip of the condoms because they are convinced that the loss of semen outside the womb will weaken their body and generate disease.

Jaya Karuppayee : When women suggest the use of condoms, immediately the male clients will ask: are you carrying an STD? Are you an infected person with the disease? Is that why you want me to use protection? But the client argues: "I do not want to wear it, I will go to see the next one". If she does not want to lose her client, either the client pays more because he does not care (drunken mood, self-confidence in the "power" of his body), or the lady has no choice but to guarantee him that she is not at risk.

Usha Raghavan : The awareness of HIV/AIDS is existing but both clients and ladies have their own interpretation: it is a foreign disease and more precisely a white man's disease. They always search for visible signs, they elaborate strategies to refute the danger, that it cannot exist in their own community (caste), that it cannot happen within their family. That is the main reason why many clients refuse to use condoms. They haven't felt the need. They have not started seeing the death. More celebrities have come forward in some other countries and said without fear that they have been infected with HIV. Not yet in India. I have worked in various countries in Africa and in the United States as well. I remember an African president who came forward and declared that his son was infected with HIV/AIDS and later died. In India, voices have not yet been raised. How many celebrities will be in a position to claim their status? I am afraid that right now, none of them want to do so. It would be, however, therapeutic. The

public can hardly imagine that HIV has appeared so dramatically everywhere in India. In some places, whatever the people come to know, to hear or to see through IEC (information, education, communication) they prefer to ignore.

David Thiagarajan : We have been working in the AIDS awareness field for the past six years in Madurai city and suburbs. We have faced many problems and much criticism. Even other NGOs once gave false news about Image, that we were promoting prostitution and so on. Despite this, we continue to work sincerely. Distribution of condoms in Madurai city is, as I said earlier, one of our main goals. In Madurai, the prostitution is of a different type. But we have to say that still today, in most of the places, condom usage is deficient. In the cheap brothels which are near the bus stand and near the pick up points (place where clients are taken to brothels and/or lodges), the clients are given a limited time, only five minutes. Generally, there is an understanding between the manager and the sex worker. For maximum five minutes, there is no time to use a condom. The women will think that if a man uses a condom, he will take more time to ejaculate, and in the present case the man is paying for a shot with a very limited time. If the man stays more than five minutes, the lodge manager will come and knock on the door, urging the couple to get out. The man has to pay twice if he does not go out immediately. So using condoms in this kind of lodge is not possible. In brothel houses, we are giving awareness to the sex workers every month or twice a month because there is a turnover of girls. The new sex workers who are employed or coming from time to time in the brothels are more able to refuse to have sex with the clients who have taken alcohol. But then, some of the sex workers, within two months, are forced to drink or initiated to alcohol. Becoming drinkers themselves, they do not refuse to work for alcoholic clients. Worse, the sex workers who are inebriated, don't bother to use condoms. The girl will not be able to remember how many clients came and enjoyed her the day before. Drug addiction is also common: pills, tranquilizers, ganja but rarely heroin. There may be self-help groups of prostitutes, but it is not common in my area.

Edward Laurent : Unlike the men who, being aware of HIV/AIDS, will bring a new razor to the barber shop, and insist on using the razor owned by them, the same person will not use condoms. It is a side-effect of the target group prevention campaign: instead of contacting only the sex workers, awareness should as well concentrate on the general public. I will give an example. In the village, the so-called rich people own a razor set. Nobody else will touch that razor. Only he will use it, wash it and to keep it. Whereas the poor people in the shop have to share the same razor. It is the same thing with the use of condoms in the cheap brothel where low class people go. They use the same girl in quick, unhygienic and unprotected conditions. While rich people go to call girls who have a restricted clientele..

Dr S. Subramaniam : We have to analyse both sides, the clients and the sex workers. When the client becomes inebriated, he will then generally not use condoms at that time. Because once drunk, he forgets everything. And even if he wants, he would not be able to put on the condom himself. Are the sex workers willing to put the condom on the man if needed, or do they just wait for the man to do so?

David Thiagarajan : The situation has changed and they are not shy about putting condoms on men's penises. The newcomers and young ones may face difficulties in the beginning, but they learn quickly. There is no repulsion in this. Another problem with us, NGOs, is that we are forced to have targets and achievements. We have to select some targets, we have to show the corresponding achievements which sometimes are not the most important realizations according to us (the number of condoms given out in one month, for instance). Imagine that in order to achieve the targets imposed by the funding agencies you decide to focus on brothel sex workers. But what about the customers ? You do not know who are they, what are the social mechanisms that lead them to the brothel and so on. You simply ignore it. Because it is not on your agenda, in your guidelines, etc. You have to show some progress in your programmed action. If you realize in the course of time that you have chosen the wrong target group, you will be criticized if you deviate in the matter. But how to explain your conviction, the necessity for a change in your action? It is a great dilemma. The apex body which wants an intervention on a particular aspect and not another will suppress the budget and your project will come to an end. However, we are aware that is time to change: instead of concentrating on the commercial sex workers we should shift to men as well.

F. Bourdier : I know David Thiagarajan well after having worked along with him during the last two years. His scope of action in Madurai goes largely beyond the field of prostitution. He has been struggling for the rights of the dalit people during the last twenty years in villages by trying to organize them, sometimes at the risk of his life. He is very particular to integrate his approach to sex workers into a broader socio-economic context.

K. Santosh : Speaking about women in prostitution led the authorities, the NGOs to consider them as a "high-risk group". This concept has been extended to many other groups in India. It has some policy implications and resonance among the population which are not without danger. That is

why Usha strongly rejected the idea that sex workers are the vector of the disease. From a human point of view as well as from a scientific one, it has to be refuted.

F. Bourdier : Effectively, a problem has arisen in our discussion when speaking about a group at risk, or a vulnerable group. The expression "groups at risk" has an epidemiological background, but most social scientists have for long been pleading for the need to change this designation into another. Moreover, it has an ideological content in the sense that it supposes that a society is compartmentalized in heterogeneous groups, each one of them having a homogeneous pattern. But it is always controversial to consider a group as a whole. It gives a caricature of an imaginary, static, segmented society. I agree with those who argue that it is more adequate to use a more comprehensive concept like "situation or social configuration at risk" which is a more inclusive, dynamic and less discriminatory concept.

Dr Venkatesvaralou : We speak about sex workers and then automatically about condoms. The use of a condom is not 100% safe. I heard not only from many experts but from an infected person who said: "I used condoms but I got infected with HIV". Many people also do not know how to use condoms. A condom does not guarantee safe protection. Some persons may ask: "How many times do we have to take it? When? With whom?". There is no doubt about the risk of using a condom. We used them for the family planning programme but the failure rate was about 30 to 40%. It means that the sperm has entered via the so-called cover. As far as HIV is a virus, the possibility of entering through the cover is also there. The second problem is how to use a condom? How to wear a condom? How often must it be changed? The people working under me in the Pondicherry AIDS cell did not receive proper training. So how can they advise others? Thirdly, promoting the use of condoms induces improper ideas about sex. Adolescents may talk about sex and develop the desire to have intercourse because they have heard about condoms. People will be encouraged to go to brothels because of condom promotion. It will definitely affect the morality of the people. Recently there was a proposal by an NGO, which wanted to intervene with higher secondary school students. The first aim was to create awareness among them. The second objective was a programme of condom distribution. I rejected the proposal. It gave the wrong impression that HIV/AIDS can be controlled by the use of condoms. One should not talk about that to them.

John Dalton : (Standing, speaking in a defiant manner) : What do you speak about? *Your* morality or *my* morality? You are completely confusing prevention and chastity. It is not acceptable, either being Indian or non-Indian. I am terrified to hear such irresponsible statements from a director of an AIDS cell who represents the public and secular sector. Your duty is to provide awareness and not to select those who are liable to hear and those who are not allowed. You feel proud to have rejected the proposal under the pretext of a non-culturally acceptable promotion of sex. You should remember that if you deliberately decide not to inform me about a deadly danger, you *kill* me. Every Indian citizen, irrespective of age, has the right to receive proper and objective information on the epidemic. Hiding the facts is nothing but a crime.

F. Bourdier : Dr Venkatesvaralou have raised an important issue that automatically leads to controversy. To argue and to discuss are the reasons for the seminar to be held. People are here to react. I do agree with John Dalton that the government has to disseminate the message to the entire population. The young generation should not be the victim of our preconceived ideas. One cannot distinguish between who has the right to know and who does not have the right. You seem to have chosen your ethic of conviction against your ethic of responsibility. Try to think about this. Anyway, there are scientific social studies all over the world which have shown that making condoms available does not increase sexual activity. Please, do stop using the false correlation between condom knowledge and more sexual intercourse.

Dr V. Jeysingh : We did a survey in Bangalore among college students from the 10th standard 12th standard (pre-baccalaureat) and in college (pre-University) on sexual behaviour. We found that among the college students who had sex, 70% of them had their first experiences with the prostitutes. Out of the 70% of college students who had sex with the prostitutes, 40% did not use a condom. They did not use condoms, not because they did not know the danger, but because they were ashamed to buy it and to put it on. At the same time, they didn't know how to use a condom. Our institute conducted awareness programmes in schools on HIV/AIDS, but in the government schools we were stopped from exhibiting to students how to use a condom. There was no other option but to stop. Then we went to other schools. They wanted us to give a lecture on HIV/AIDS, but they did not want us to talk about condom usage. They did not want us to talk about it because a lot of parents came and complained by saying: "Do not teach that to my son (or daughter)". We again had to stop because parents objected to such an education. "Our children have to be educated; you have to guide them in a proper way". It means that we have to educate parents first?

² A brand of condom which has become a generic term.

Dr P.K. Das : I would like to temper the conflict. In fact, there is no conflict at all, but participants are talking in different ways. Dr. Venkatesvaralou was the first to object to sex education in the name of morality. What he is trying to express is that new education will expose students to new ideas. Parents see what is happening in Western culture regarding HIV/AIDS. So they are afraid that if same messages go to their children's school, they will be affected. That is why the parents are objecting to this type of modern education. In that case we have to educate the parents before the school children. These are types of approach which are different, not in nature, but in hierarchy of order. I have been working with the NGOs since they emerged nearly twenty years back. Fortunately, I was very enthusiastic when they started. I was thinking that they would fill the gaps separating the researcher, the medical staff and the people in the community. But we are still waiting. We look at one side of the coin and go and try to impose it. I have realized that paradoxically NGOs are very directive and not flexible. It has earned them a very negative image and their impact is in some places ambivalent. We don't mind in educating the children, but in the right manner. What is wrong in trying to define what we mean by "right manner"? In the case of AIDS, if the parents object, first you have to educate the parents. Then you go to the students. Then you have better acceptance. We also have not to rely on external assistance. Everybody in his life should act with humanity, that is to say as a social worker.

F. Bourdier : The students in contemporary India have not waited for the prevention campaigns to be exposed to or influenced by the West. Television, modern movies, satellite cables, youth magazines, etc. are available everywhere, even in many rural areas. It is time for the adults and for the educators to take into account the contextual situation of pluriculturalism. The good old time is no more. I know that in India, the time perception is cyclic. It induces persons to believe that everything may come back...

Dr. Venkatesvaralou : Dr. Das said each person is an NGO because he himself is competent to talk on AIDS/HIV. HIV is not something that everybody can talk about knowing what it is. Actually, as Dr. Das pointed out, I have written to the Directorate of Education not to allow anybody to talk on HIV/AIDS in schools, unless they have been authentically trained. Only resource persons may be authorized. Because wrong news, incorrect informations is too often given. Free license given to NGOs to talk on HIV/AIDS may be dangerous. We have to check their knowledge before. What are the criteria? What are their qualifications? In my department, no medical officer can go on talking without knowing HIV/AIDS. Among the thousands of persons willing to create an NGO, I really wonder how many of them are competent to talk about HIV/AIDS? Are basic qualifications prescribed ? By the government or by any licensing authority ? Give me some clarification.

F. Bourdier : Three points should retain our attention. First, like in every lucrative occupation, one will find opportunistic persons trying to take advantage of the advance of the epidemic in order to make money out of it, to gain prestige or to earn other social advantages. I have encountered such groups of persons in Tamil Nadu and elsewhere. A lot of money is dispatched for HIV/AIDS and people are well aware of it. Second, you talk about the necessary qualifications of the NGOs. Government health administrators and private doctors have to be educated as well, not only NGOs. It is a general process which has to reach the leading segments of the society who are in charge of communicating, informing and educating the population about the epidemic. If the public administrators themselves come forward and try to subordinate the others, here starts the Daedalus problem of hierarchy and jealousy. Third, you mention about wrong information. We agree and recognize this as a matter of fact. But you should also add misinformation and the absence of sufficient information.

Impression of Implementation Project on HIV/AIDS in Maharashtra
Dr. Shukla, J.Y ., Dr. Mrs. A. Mhaskar - Chief Sociologist, Miss S.A. Kelkar - Social Worker, L.C. S. Sabnis - Chief Manager, Nashik
(Maharashtra)

Introduction

The Maharashtra T.B. Sanatorium is an old non-governmental organization working in the field of tuberculosis since 1934. It is located in Nashik in the State of Maharashtra, about 180 kilometres from the state capital Mumbai.

The sanatorium has been, since 1969, managed by the Nashik branch of the Indian Medical Association (IMA). It is situated on five acres of land (about two hectares) and has complete infrastructure to accommodate 120 patients, with all the facilities to treat and investigate the in-patients. Five consultant chest physicians, one resident doctor, as well as a chief sociologist (a doctorate in sociology), and two social workers attending to sociological and non-clinical aspects of the patients, are working in the sanatorium. For clinical work, sufficient paraclinical staff is available.

Beginning roughly in 1992, the consultant physicians started finding that a number of cases showed deterioration without responding to drugs, and that there was an increasing number of Mortality Death Rates (MDR) cases.

Subsequent to discussions among themselves, as well as with the management and members of the Nashik branch of the IMA, a mandatory HIV testing on all patients was considered. All the aspects of such testing were deliberated, including counselling and confidentiality. It was felt that the advantages of a mandatory HIV test outweighed other aspects.

Such mandatory testing was instituted in January 1995. Since then, we have detected 112 cases of HIV infection amongst TB patients up to May 1997. We started in June 1977 a project on AIDS in our institution. As the project on HIV/AIDS envisions a prospective study of such cases, it was decided to carry out a retrospective study of these 112 cases :

Total admissions from January 1995 to May 1997	2195
HIV-positive cases detected	112
Percentage of HIV-positive cases	5,1 %

This percentage of patients does not reflect the true picture. Some cases were referred with HIV-positive status. Unfortunately, such cases were not taken on record as HIV- positive, but treated in the sanatorium. As the number of such cases is very difficult to assess, the percentage of cases is lower than as reflected in these statistics.

The socological research

- The objectives of this retrospective study are defined as follows:
- a) to study the natural history of HIV-positive tuberculosis ;
 - b) to find out, if possible, the presence of HIV among family members ;
 - c) to study the socio-economic impact of HIV on the family members ;

d) to undertake at a later stage case studies of a few families.

The methodology used to carry out this study is as follows:

1. As a first stage, letters were dispatched to all the patients inquiring about their health. They were accompanied with reply-paid cards so as to get responses from the patients.
2. The next stage is to go to the residence of patients who have not replied, to find out their current status and difficulties. Visits are also being planned to those patients who have replied to our letters.

The objectives of home visits are:

- 1) to find out the reasons for failing to come for follow-up at the sanatorium ;
- 2) to obtain first-hand information about the socio-economic status and lifestyle of the patients ;
- 3) to provide some guidelines for the selection of families for case studies ;
- 4) to ascertain the exact cause of death as certified on the death certificate.

With these remarks, the present preliminary statistical data collected until 30/09/1997, are tabulated under:

Table 1 : Distribution of patients according to the geographical area :

S.NO	DISTRICT	NUMBER OF PATIENTS	PERCENTAGE
7			
1	Nashik	86	76,78
2	Ahamadnagar	15	13,39
3	Thane	05	04,46
4	Mumbai	04	03,57

5	Dhule	01	00,89
6	Pune	01	00,89
TOTAL		112	100%

Table 2. Taluk-wise distribution of Nashik District :

S.NO	AREA	NUMBER OF PATIENTS	% OUT OF 112 CASES
1	Nashik City	44	37,05
2	Niphad	12	10,71
3	Igatpuri	10	08,92
4	Sinnar	08	07,14
5	Dindori	03	02,67
6	Chandwad	02	01,78
7	Malegaon	02	01,78
8	Kalwan	02	01,78
9	Surgu na	02	01,78

10	Manmad	01	00,89
11	Bhagur	01	00,89
	Total	86	100%

Table 3 : Age-wise distribution

AGE	M	F	TOTAL	PERCENTAGE
15 to 20	00	01	01	00,89%
21 to 25	23	04	27	24,40%
26 to 30	31	01	32	28,57%
31 to 35	12	01	13	11,50%
36 to 40	12	05	17	15,17%
41 to 45	06	01	07	06,25%
46 to 50	06	03	09	08,03%
51 to 55	05	00	05	04,46%

56 to 60	01	00	01	00,89%
60 to over	00	00	00	00,00%
TOTAL	96	16	112	100%

Table 4 :Gender-wise distribution

	MALE PATIENTS	FEMALE PATIENTS
MALE	96	85,71%
FEMALE	16	14,29%
TOTAL	112	100%

Table 5 Type of Response to Letters

Death confirmed by relatives through letter	19
Answers received from the patients	10
Patients attended follow-up	03
Letters returned because of incomplete addresses/ resident having moved	08
Total	40

Table 6 : Percentage of deaths calculated from the letters responded to by relatives of patients.

Total response received	32 cases
Deaths	19 cases
Percentage of death	59.37 %

Based on the foregoing statistical data and on our impressions, the conclusions are as follows:

- a) Tuberculosis and HIV are a deadly combination. Death occurred within a period 3 to 6 months from the detection of this combination.
- b) Drug compliance is very poor in such patients. This is one of the causes of early death.
- c) Observed treatment is best for such patients. Ideally, they should be admitted to an institution like ours for a period of not less than three months, where drug compliance is best. Unfortunately, the finances of our patients and of the institution do not permit of the admission of such in-patient treatment free-of-charge.
- d) As far as counselling is concerned, we feel that the present concept of counselling with a stress on safe sex practices is not adequate in our milieu. The role of counselling should be institution specific. Here the situation is such that patients have hardly any sexual desire or contact. Under these circumstances, counselling on these lines is meaningless, and we prefer to stress drug compliance and better nutritional practices. This may give a better quality of life for a longer period of time.

We feel that there are no specific prescriptions or guidelines concerning counselling. It should be situation specific, relevant and rewarding both to the patients and to the counsellor. Several comments were made to us before starting the programme of writing letters for follow-up to HIV patients. First, we were said to be exposing ourselves to a breach of confidentiality by writing letters to HIV-positive individuals, and second, we were exposing ourselves to discrimination by writing letters and planning for residential follow-up of HIV-positive patients.

These remarks were made by persons of high standing in the field who are authorities on the subject. Hence we have termed them curious remarks. With these remarks in mind, we have decided to go ahead with our projected programme and face the situation as and when it arises.

We want to raise the following questions and request advice on these points from this gathering.

- 1) To what extent is confidentiality to be held?

2) Does the follow-up of one's patients constitutes discrimination?

These are only our preliminary observations and impressions. When the study is complete, we will be able to give a more detailed and complete report on these aspects.

The next important aspect of our project is the survey of local doctors. As we want to impart proper knowledge regarding various aspects of HIV/AIDS, we thought we should have information about the level of knowledge and the needs of local doctors. During the last few years, a number of seminars, symposia, workshops and lecture series have been held by several government organizations and NGOs. We think that we can assess the impact such seminars, etc. had on the doctors.

The methodology adopted to carry out the survey was a self-administered questionnaire. This questionnaire was prepared after discussion among all persons involved in conducting the survey. The chief sociologist conducted a few interviews with a trial questionnaire. After the pilot survey, the design of the questionnaire was considered. The survey started in mid-July 1997. A total period of four months was allotted to collect the data from the doctors, i.e. up to mid-November 1997.

The questionnaire has two parts. The first part was specifically designed by our chief sociologist for the study of the sociological profiles of our local doctors. It was thought that we can approach doctors only once and we could therefore obtain data on sociological aspects in the same questionnaire. The questionnaire was designed with the following objectives in mind:

1. to study the knowledge, attitude, behaviour and practices (KABP) of doctors in our area ;
2. to study the impact of previous educational efforts on the doctors ;
3. to study areas of knowledge for doctors which require emphasis in our educational programme ;
4. to study the sociological profiles of doctors in our area.

There are about 1100 doctors within the corporation limits of Nashik who are members of various associations. It is estimated that an equal number are not members of any association. It was decided to obtain the data from doctors practising any system of medicine, irrespective of qualifications. Keeping in view our scope and infrastructure, our target is to cover in this survey about 25 to 30 per cent of the doctors practising in the town.

While the survey is still going on, we have received 397 questionnaires from doctors as of 30 September 1997. We wanted to give a complete analysis of questions, but due to circumstances beyond our control, such as computer software failure, we cannot give a complete analysis. A few questions which have been analyzed are being presented as a preliminary study of the survey. With these remarks, I turn to the data collected by us.

Question 11

Have you come across in your practice any HIV- positive person?		
Yes	201	50.7
No	167	42.0%
No response	29	07.3%

Total	397	100%
If your answer is yes, what is the approximate number?		
1	46	22.9%
2 to 5	93	46.3%
more than 5	62	32.8%

Total	201	100%

The conclusions drawn from this are:

1. A majority of doctors have seen a case of HIV infection in their practice. Hence they are aware of the infection and they have some knowledge of it and of its clinical manifestations.
2. A surprisingly large proportion of doctors have seen more than 5 cases of HIV/AIDS in their practice. This data is in our view not concrete, and will only become available on completion of the study.

This does not give any idea of the prevalence of the disease in the society since one patient may have several doctors. The impression created is that the infection is spreading rapidly in the society.

Question 13

Is AIDS a notifiable disease? (like cholera, polio, etc.)?		
Yes	73	20.4%
No	285	79.6%

Total response	358	100%
If your answer is no, should it be made a notifiable disease?		
Yes	190	56.5%
No	146	43.52%

Total	336	100%

Question 14

While considering the issues involved in HIV infection, whose interest is paramount according to you?		
Society	268	72.4%
Individual	60	16.2%
Both	42	11.4%

Total	370	100%

The conclusions drawn from the responses to these two questions are:

1. Most of the doctors are aware that HIV is not a notifiable disease, but a majority of the doctors feel that it should be made such.
2. An overwhelming majority of the doctors feel that society has priority over individuals in connection with HIV/AIDS problems.

Taken together, these answers reflect that doctors give importance to society over the individual when considering the issues involved in the HIV/AIDS infection.

Question 18

Do you feel that AIDS testing will be an important factor in arranged marriages in future?		
Yes	120	56.6%
No	46	21.7%
Don't know	18	08.5%
Against our social customs	38	17.9%

Total	212	100%

The response to this question has been given by more than 50 per cent of the doctors participating in the survey. In fact, this question was included in the questionnaire as an afterthought. During our pilot survey to determine the final design of the questionnaire, some doctors told us that there were a few parents of prospective brides and grooms asking whether they should ask for an HIV test by the

groom or bride before marriage. To this question we have no answer. We therefore included the question to find out the views of the doctors on this point, for it is usual for many people to ask doctors health-related questions regarding the prospective bride or groom.

The statistical data is revealing. The majority of doctors responding to the question feel that it is going to be an important factor in arranged marriages in the future. Keeping in mind that today in India, most of the marriages are arranged, it is of great importance. We will have to consider it from the point of view of confidentiality and discrimination. In order to provide us with some guidance, I would request the audience to discuss this aspect thoroughly, namely: Should we ask for premarital HIV testing of prospective brides/grooms?

Question 25

Will you treat HIV-infected patients in your clinic or hospital?		
Yes	137	36.7%
No	236	63.3%

Total	373	100%

Question 26

Will you treat HIV-infected patients if proper facilities are provided by an institution?		
Yes	270	84.4%
No	50	15.6%

Total response	320	100%

The statistics tell us that:

- 1. A fair percentage of doctors in our area are willing to treat HIV/AIDS cases in their private clinics/hospitals.
- 2. A majority will treat such patients in an institution where all facilities for treatment are available.

The conclusions drawn from the above observations are:

1. The survey shows that a majority of doctors are willing to treat HIV/AIDS cases if they are given proper facilities/knowledge.
It brings out the fallacy expounded by various reports in the press that a majority of doctors would not treat HIV/AIDS cases.
2. Doctors, at least in our area, do not consider the HIV/AIDS infection as something which should be shunned.

This conclusion, considered along with the conclusion drawn from Question 11, gives probable reasons for the willingness of doctors to treat such cases. They consider it as a purely medical problem. They have accepted it as an evil which is going to stay with us and have, therefore, decided to contribute their efforts in the battle against this infection.

Question 27

Which organizations are working for the prevention and control of AIDS?			
1. National Level:-			
2. At State level:-			
No response	275	69,3%	
Doctors answering the question by giving some name	112	28,2%	
Answered don't know	1		
0	02,5%		
		-----	-----
Total		39	100%

Analysis of answers:

Only the top five organizations were represented in the responses.				
<u>At the national level</u>				
	percentage of total response		of 112	
1. WHO	17		15.2%	
2. NACO	15		13.3%	
3. National AIDS Research Institute		11		09.8%
4. SOS FOUNDATION	04		03.5%	
5. ROTARY CLUB	03		02.6%	
<u>At the state Level</u>				
1. Maharashtra government	20(27)		24.1%	
2. JANKALYAN Blood Bank	20		17.8%	
3. Maharashtra TB Sanatorium	09		08.0%	
4. Indian Medical Association		04		03.5%
5. NGOs	04		03.5%	

Conclusions drawn from above data are:

1. No one responded with "Don't know".
2. Hardly 30 per cent of the doctors have any idea of organizations working in the field of HIV/AIDS.
3. At the national level, NACO, which is the apex body to coordinate efforts to control HIV/AIDS, is known to 13.5 per cent of the doctors responding to the question, while it is known to less than 4 per cent of 397 respondents.
4. At the state level, 27 respondents say that the government is working in the field, which comes to 25 per cent of the total respondents answering the question.
5. The doctors have responded by naming organizations like ours as working at the state level while, in fact, we are working at the local level.
6. Sevadham Trust, an organization which is a nodal agency to coordinate the efforts in the field for the state of Maharashtra, is known to less than 4 per cent of the respondents.

The implications of these conclusions are:

- a) The various organizations working at state and central levels do not have good public relations.
- b) In spite of the fact that NACO is an organization sponsored by the central government and has all the means of publicity at its disposal, it is not utilizing these assets.

The reasons can be:

1. inefficiency at the organizational level;
2. lack of public relations and co-ordination with proper agencies involved in publicity.

The same reasons apply for state-level organizations working in the field.

These are preliminary observations on data from the survey. In the next few months we will be able to complete the survey and analysis of the complete data.

After these comments, I would like to turn to some other aspects related to HIV/AIDS and involved issues. Our physicians are studying the natural course of HIV with tuberculosis and its clinical presentation. They will be presenting papers in proper medical/ scientific fora from time to time. Here we will consider non-clinical issues.

In the following we will present our observations and opinions regarding the issue of confidentiality and HIV status.

1. The socio-economic strata from which our HIV- positive TB patients are drawn have no idea of confidentiality. The concept is alien to them. They come from fairly large close-knit joint families, where day-to-day living expenses and medical care are looked after by the family as a unit. Under the circumstances, it is almost impossible to preserve the confidentiality of the HIV status. The head of the family, who is making efforts and spending money, wants to know the kind of ailment from which his ward or relative is suffering. He needs to know this in order to plan his expenses and to make arrangements for financing the medical care of his family member.

Confidentiality as a higher philosophical concept is completely alien to Indian philosophy and culture. It is a typical Western concept in which the individual is given priority over the society. Indian philosophy and culture have for millennia given importance to society over the individual. My argument is that reference to Sanskrit and Buddhist scriptures shows the underlying principle that the group or society is more important than any individual.

Thinking about this concept at another level, it is a struggle for supremacy between the individual and society. When we take an approach based on Indian philosophy and culture, our view on this matter will be much different. Otherwise we would not have been advised that approaching HIV-infected patients by means of a letter or home-visit would be a breach of confidentiality, or that we should not tell anyone about the HIV status of the patient, not even those who are caring for him. NACO and other organizations participating in sixty-five city surveys, have for many years been hiding behind the notion of confidentiality and not disclosing their data.

In conclusion, we must find our own solutions to various aspects of the question of confidentiality so that an individual is protected, but society at large does not suffer. This subject should be discussed until a certain consensus is achieved.

We have reached certain views about counselling. In our experience, pre-test counselling is alien to our patients. They do not understand the importance and implications of pre-test counselling. After listening to the discussion during counselling, they will give the doctor blanket permission to go ahead and carry out any investigations he wants. Post-test counselling is something which they do understand, because this is something to which they are accustomed in all medical situations. We feel that pre-test counselling should be dispensed with and only post-test counselling followed.

Difficulties and constraints encountered

We would like to place before this gathering of intelligent and public-spirited persons some of the difficulties and constraints faced by us. We do this in an attempt to find solutions to these problems.

a) The apex body, NACO, which is coordinating the efforts in the field of HIV/AIDS, is inactive. We have not received a reply to a single letter sent to them. We have therefore stopped writing to them.

The publications of NACO are not available anywhere. We had to make photocopies by begging from people who had these publications, but it is a very costly proposition to acquire them in this way. The only government publication reaching the people was *Caric Calling*, publication of which stopped a few years ago. Thus, the only authentic source of data and information is no longer available.

In short, NACO is perceived by us as a very unenthusiastic and public-unfriendly apex body. This is not to criticize NACO, but to bring to its notice our perceptions.

b) We find that there is an acute need for a directory of organizations which are working in the field, for want of which we are unable to communicate and exchange views with other organizations. If some organization were to take up the work of compiling such a directory, it would be a great help to all of us.

c) As regards financial constraints, the sanatorium is self-financing. We do not ask for grants from any organizations towards the running of the sanatorium. We did once receive a grant from Government of Maharashtra for an AIDS project, for which we are greatly obliged. In fact, some of the work presented here was possible due to this grant.

We find that funds are needed for the acquisition of equipment, etc. for sophisticated investigations concerning HIV/AIDS. We have no knowledge about funding agencies providing such grants.

Another area where we find need of funds is in the treatment of tuberculosis patients with an extremely poor economic status. Most of them need admissions for continuous weeks and must spend about Rs. 4000 during this period. Because the sanatorium is self-funding, it cannot afford to admit them free-of-charge. They must therefore be turned away. Occasionally, some philanthropist pays for a patient, but we are not in a position to help most of them.

Lastly, we have one suggestion. The government of India has launched a revised Domiciliary Observed Treatment Scheme (DOTS) for the treatment of tuberculosis. It includes distribution of drugs for sputum-positive cases only. We suggest that the government should also include cases of tuberculosis with HIV infection for drug distribution under DOTS.

Discussion

F. Bourdier : Doctor Shukla you are a representative of the private sector. You have undertaken a study on HIV/AIDS epidemic perception among biomedical doctors. In your paper you are suggesting some communication problems faced by the national bodies in India, specifically in the case of NACO (National Aids control Organization), and centres like the one to which you belong. You have raised some ethical points which will be discussed in the next session, like the priority of society over individuals, for instance. Your contribution has the advantage of showing how research as a production of knowledge is important for self-reflection and self-evaluation. In fact, you are questioning the functioning of the structure and you are putting forward the discrepancies in it.

Dr S. Sivaraman : Regarding the last point Doctor Shukla mentioned, I have to add something. You are speaking about the launching of debates on the National Tuberculosis Control Programme. I think that there is a misconception in the minds that the revised National TB Control Programme does not provide services for the infected HIV/AIDS patients. This is wrong. The revised National TB Control Programme just classifies all cases under various categories. The first category is infected TB patients. The second category is the failure case and category three is a specific provision that concerns other problems. You can treat non-infected HIV patients and HIV patients as well. You can treat the later for longer period treatment as they fall into the first category, provided they are clinically serious cases. The problem is not there. Another misconception is more important. People tend to link TB with AIDS. The government is very careful about that. Take the manual of the TB National Control Programme. There is a whole chapter on HIV along with TB (as the main opportunistic disease). So I think that it clarifies the false relation people may infer. Another doubtful dimension of your presentation regards the question of confidentiality, I am not going into the ethical part of it, but only as concerns the relation between TB and HIV. I am a TB specialist myself. You said that you have written letters. Under the National TB Control Programme, you should have written letters not only to HIV *and* TB patients, but to any TB patients. Like this there would be no arbitrary discrimination. No inquiry should break the confidentiality, because there are strict government rules about confidentiality. You have to write a letter to all TB patients if you follow the government rules. Naturally, because you are from a NGO, you can pick and choose. That is OK. If you write to everybody nobody is going to be know whether someone is a TB or HIV patient. Another critical aspect of your statement is about care. The concept now is primary health care. Any special TB worker or AIDS worker goes to the house of the patient. Confidentiality will not be broken. I will tell you a little story from my own experience. I was invited to an officers' dinner. There was a lady whom I knew from my profession. She is a post-graduate lecturer in a post-graduate college. The host is an IAS (Indian Administrative Service) officer. He wanted to introduce me to her, and as he did so, I realized that I knew her already as a patient. He was surprised and asked how I had come to know her. She was anxious and frustrated, you can imagine. I told him that her husband was my classmate. These are the situations that we have to manage. A last question I want to ask you: The questionnaire about the organization in the field, did it consist of multiple choice questionw or of open-ended questions?

Dr Shukla : For your information, I distributed these questionnaires in our assembly. A few copies are still available. It took about three months of part time work to prepare this questionnaire. The main use was for our medical association, not for any AIDS project implementation. It was our sociologist who wanted to study the social structures of the medical practices. So part one is mainly for the local use. The sociologist wanted to include the aims of the research in a different part about AIDS. But we could not analyse all the source manuals before September. We analysed the socio-economic aspects regarding AIDS. It was open questions. The second point is that some doctors were at that time exposed to a refresher course in a workshop or a governmental programme. Our investigation was done after a pre-test inquiry. My social workers started the field inquiry after three weeks of work. It is rare to get this type of questionnaires from the doctors. They usually don't give such importance to questionnaires. Another precaution that you say you hope that I would have taken is related to confidentiality. We made the questionnaire in two parts. We remove the name to keep the confidentiality. How do we manage to keep the confidentiality? We have to make sense of the study because if you don't write the name, the social worker will not come again and again to see you. So we gave duplicate numbers. I consider what you are saying. You are welcome if you don't write the names. But I am a senior doctor. I have a schedule for the doctors to get the information. Otherwise it is impossible to collect the merit questions. Among those intervieweed, only two persons told me that they did not want to write their names. Nobody else objected to disclosing their names. Some people asked me "Why doctor are you not writing our address and other things?". Afterwards, we made the survey available to everybody who wanted to participate in it. On the basis of this questionnaire, dissemination methodology is as important as dissemination of results.

Prof. Gurumurthy : I want Doctor Shukla to clarify a few questions. Since you are in touch both with HIV and TB patients, I would like to know if you have any break-up for the cases who have got both? TB patients have HIV and HIV patients have TB. The second point is the background of the positive cases. You just mentioned HIV and TB cases. Sex background you have given. But what about the socio-cultural and economic components? Since this morning we have been talking about prostitution and social aspects of the epidemic, such parameters are needed because once a person becomes a TB patient, then marriage prospects and employment opportunities are less. In such cases, some women may become prostitutes. That is what I am trying to connect these points. The second objection is related to the use of the terminology "Have you ever seen an HIV-positive case?". It is a different word from examining, providing care and treating. Medical terms are different. You have to be careful about that because it may lead to misunderstandings. My third question is about the assessment where you ask the pathologists if there are sufficient laboratory facilities for the doctor to make special diagnoses? For HIV, he needs special equipment. The

ones you interview are general practitioners and you are not giving any information about it. Last but not least, we do not know if all the 1100 doctors are from Nashik town, and you have not given the break-up according to category of physician, like biomedical doctor (MBBS), homeopathy practitioner, Registered Medical Practitioner (RMP), etc.

Dr Bobby Zachariah : We run a hospital in Jawadhar hills for TB patients and in our building we have in-patients facility for up to 25 persons. It is always full. 80% of the out-patients attempt to obtain hospital treatment. Secondly, about drugs for immunization for TB. We found that if the patient is using the drugs supplied by the TB sanatorium, the improvement is not as good as it is for drugs available in the open market. It is wrong to believe that the government supplies drugs in substantial quality. That is why we have to buy the drugs from the open private markets. The price is high in the open market but at least it is available. It costs about 60 rupees per dose (only for TB cure). Out-patients coming to our hospital cannot afford it. Thirdly, we found that because of the stigma attached to TB, they are not willing to buy the medication by themselves. A lot of families prefer to go to buy the drugs in non-identified places rather than maintaining the patient out of the house. Families prefer to provide them medication at home. I am talking about the lower strata of the society. In addition, a lot of people who are HIV positive are given TB medication. Some of them have allergies. These are new reasons which make them stop the medication for TB. In other words, TB patients who are HIV positive are in many respects more socially vulnerable and liable to remain uncured.

Dr Gurumurthy : Is it advisable to continue a costly co-therapy on HIV patients in that case?

Dr S. Sivaraman : I object to the declaration made by Bobby Zachariah. He said that the government is providing substandard drugs. I am a TB control officer. I am providing substantial drugs. Do you have any facts and figures that could say that governmental drugs are not effective while the drugs available in the free market are more effective in terms of quality standard? Such a statement should not be raised without facts and figures in a scientific forum like this one. TB drugs are supplied by the government of India. We have clear-cut rules, procedures and standards, and quality control is made at various levels. An independent research institution is controlling the quality and is testing the drugs before supplying them. It is at present watched over by the World Bank under the Revised Control Programme. So, please, don't make disruptive remarks without supporting them by facts and figures. If you do have figures, please produce them.

F. Bourdier : I think Bobby Zachariah was speaking about the perception of the people, which is something different. The government may be providing quality drugs or not, that is the not the question. In any case, people have their own social representations. They get the impression that drugs are of low quality because they are free, because the colour of the pills is white, and for any other complex reasons. I remember eight years ago I was studying health behaviour in three villages near Coimbatore. In one village, there was a Primary Health Care centre and the rumour was going around that all the drugs provided were inefficient, because they were small and had the same colour. Of course, as a social scientist, you cannot take this point as matter of fact. But it is people's perception and it definitely has a meaning. Not that the drug in itself was bad, but something in the public service was not right. In that case, it was the social relation with the medical staff. In other words, what the people maintain is of importance: whatever it is, we have to find out the hidden structures behind it.

Dr Bobby Zachariah : It is also there. But when you are talking specifically about TB patients and medication it implies availability of four drugs. It is difficult for patients when they go to a TB sanatorium to get all the four drugs simultaneously. TB Sanatoria will have only two or maybe three of the drugs. They will not have all of them. Patients have to go to other places to get the remaining one(s).

Dr S. Sivaram : The government has a network of primary health centres. These primary health care institutions provide free drugs. Sanatoria are concerned only with in-patient treatments. I have been chief of a TB sanatorium and am now chief of a district TB sanatorium. So I have experience in both. After having been discharged by the sanatorium, the patients take care of themselves. Any patient who has not been admitted and who is going for domicile therapy has to approach the nearest primary health centre and has to ask the district tuberculosis centre for drugs. There is an index which is maintained at the district level and they will be given drugs if they are included. There may be some indifference because of logistical problems, I don't deny that. But everybody is getting drugs. Most of the time, because of the revised National Tuberculosis Control Programme, dearth of drugs is not common. It used to happen, I do agree. Because there is logistical support, there will be logistical problems. There is one cell in Delhi. When I asked the question "Why, sir, are you not supplying drugs?", he replied

"Come and see me. You will see my staff. I have 412 districts in India to look after but I have a staff of five people including one personal assistant, one clerk and one store keeper. That is all I have". This sort of logistical problem is there. Whom do we have to accuse?

Dr Shukla : One of your questions was whether the case be HIV or TB. Now that we are giving interest to research study, we do need information. But, regarding HIV and TB, is difficult to find out who is what. There is a separate questionnaire which we have prepared. We have not distributed it to everybody. We will give it only to those who are really interested in prospective studies. If it is relevant, from that prospective study we can find out what comes first: whether TB or HIV. Regarding what Professor Gurumurthy said when asking doctors about their confrontation with an HIV patient, it does not mean that the doctor had ever examined a patient. It does not mean that a doctor had seen HIV or TB coming first. But it means that a doctor, in particular cases, may be in position to assess the clinical evolution of his patients.

Male respondent : My point is whether a clinical test is needed to determine whether a person has HIV or not.

Dr Shukla : I am coming to that. There is a misconception that the HIV test is something very difficult to undergo. Nowadays, if you take an HIV test with the modern technique which is available, you will realize that there is no point of being anxious. With modern techniques, it costs less than 80 rupees and even a small boy can do it. It does not require beds or other costly facilities. It does not need much of technique, a reliable test can be done in the laboratory of the clinic. So do away with the concept that this is very difficult task. It does not require any particular knowledge or equipment. You simply buy a kit and everything is available in it. Coming to the advanced stage of our research: it is still going on and I did not give you a final result. One of our concerns is to know why doctors are reluctant to deal with HIV patients and what should be done to improve this situation. Treating a patient is natural and a must. But doctors are also human beings. They have personal fears about getting infected through injections, needles, etc. These small facilities are available in all the clinics. It is one of the reasons why the doctors are not willing to treat HIV-infected persons. Some of them cannot treat the patient and simultaneously change their materials. But another idea which generated a lot of discussion with a number of government and private doctors was about the general view that doctors within the next five years will have to treat HIV-positive patients irrespective of their initial decision. Simply because, if five to seven per cent of the population in India is HIV positive, than fifty per cent of the doctors will treat HIV-positive patients. It is a mathematical prediction that replaces the problem in an objective way.

F. Bourdier : From the research point of view, you have raised two issues which will be discussed in the two following sessions. The first one is about the medical and legal aspects of the epidemic. The second will be challenged, I hope, during the session dedicated to the role of NGOs regarding medication, and their ambivalent relations with government and international agencies.

" It is not a new reading of society that must be
undertaken, society must be re-written"

Robert Mallet, *Apostilles in Notes dédiées à Jean Poirier*, PUF, 1997

*To William, Alice and Sylvia
and many others*

Introduction

Dr Subramaniam : It gives me very great pleasure to welcome you from all regions of India to take part in this workshop on NGOs involvement in AIDS/AIDS prevention and care. The Indian Society for Environmental Health (ISEH) from Madurai and the French Institute of Pondicherry together have attempted to gather various personalities involved in one way or another in the struggle against the epidemic. Such a meeting responds to the urgent need to arrive, during these three days, at a relevant analysis of the social problems we have all faced so as to better understand the epidemic. Nobody would deny the necessity of a national policy which has to be decided by the government agencies; but, we all know that their scope of action is limited. On the other hand, NGOs are supposed to be in a position to reach the lowest strata of the society, which are usually not reached by national bodies.

For instance, many of you interact with commercial sex workers, try to understand their level of vulnerability in a patriarchal society, and try to empower them by promoting awareness, preventive methods, safer sex and social rehabilitation for those who want and who are in a position to be rehabilitated. One of the main objectives of the NGOs' action is to try to prevent people from becoming infected by informing them not only about the biological risk represented by unsafe sex, but also about the extent of mental degradation resulting of drugs. Places like Manipur, Mizoram, and to some extent Assam, have become notorious for the dramatic number of intravenous drug users (IDUs) who have become HIV-positive.

Mumbai, which is the commercial capital of India, now has more than 50 000 HIV cases. Madurai, from where I come, is known not only to be a pilgrimage centre, but is also noted for its prostitution. The "cultural" city of the South has a reputation for being a permissive place for sex, and for having an evident and highly complex network of prostitutes, pimps and other persons involved in the sex trade. At present, more and more communication areas where lorry drivers are centred, like Narmakkal in Tamil Nadu, are challenging the prevention campaigns. In fact, the country as a whole faces the epidemic, whether rural or urban areas, southern or northern states. Nobody, irrespective of class, sex and caste, can think to be safe. Again, that is why we have come together to exchange the ideas and learn from each other's experiences in order to make a safer place to live for everybody.

F. Bourdier : Along with the Union Territories of Delhi and Pondicherry, twelve states of the Indian subcontinent are represented in our assembly : Rajasthan, West Bengal, Orissa, Maharashtra, Goa, Madhya Pradesh, Manipur, Mizoram and the four South Indian states of Kerala, Tamil Nadu, Karnataka, Andhra Pradesh. One of the purposes of the workshop is to give a bird's eye view of the national situation and, most of all, to interact in a constructive way. I have been very insistent that this seminar be conducted in an informal way: no very important people (VIP) will preside at the seances, nor will there be any other unnecessary speeches. There will be no ceremonious functions such as are usually held at symposia in India. I do hope you have come not only to listen to others and present your own ideas, but eventually to learn from the experiences of others to evaluate the potential collaboration among people of different backgrounds. For my part, as a researcher in social sciences, I am interested in knowing about

the nature of the problems that NGOs, government representatives and activists are facing both at the designing stage and at the implementation stage of the projects.

The particularity of this assembly is that it is composed of persons with extremely varied occupations: doctors, epidemiologists, public health officers, health administrators, while others are members of NGOs, representatives of international agencies, researchers, community delegates, human rights activists, legal aid advisors. Due to our profession, each one of us is dealing with social aspects of the HIV/AIDS epidemic, most probably from a particular perspective. As far as the workshop is concerned, the diversity of our different approaches, our different perspectives, is undoubtedly our strength. Through our combination, we have the potentiality to facilitate the emergence of new ideas, if we are ready to accept the arguments of others.

Those who have joined the seminar are mostly from the private sector. In the field of HIV/AIDS, NGOs encompass a vast domain : from focus interventions to more integrated approaches in which the epidemic is just one of the components. On the other side, social scientists who are present in the assembly are generally not directly involved in action. However, whether they are sociologists, anthropologists, geographers or psychologists, they have the capacity to analyze the facts and figures of the Indian situation in as objective and neutral a way as possible. Ultimately and theoretically, their findings should provide some insights. They may enable the deciders to orient their programmes, and they may help the social workers to have a better understanding of the various sociocultural contexts in which their actions are supposed to take place.

After a few years in India, and after numerous contacts and close relations with NGOs, I have come to realize that there are a set of misconceptions about: 1) the nature of the research; 2) the relevance of research; 3) the purpose of research; and 4) the difference between social action and social research. One of the final objectives of the seminar is to clarify what potential benefits and advantages one may get by taking into account the findings of social research. During these three days, we are going to review a state of the art of NGOs' various implementations strategies. The panorama will not be exhaustive insofar as only a limited number of NGOs are represented.

Lastly, I have to point out that due to 1) the constraints of time, 2) the importance to be given to constructive discussions and, 3) the large number of papers received, it will not be possible to give everybody an opportunity to present a paper. It has been decided to try to avoid repetition, similar projections, common statements. Priority will be given to innovative papers. But more important than the papers themselves, the outcome of the seminar depends on everyone's participation.

Part One

Points of View of :

Leaders of Community-Based Organizations

Social Researchers

Doctors

From Understanding to Action

Frédéric Bourdier, Equipe "Sociétés, santé, développement", Université de Bordeaux II,
Bordeaux (France)

Nobody can deny that if AIDS is the physical manifestation of a biological disorder, the epidemic is the reflection of a social phenomenon. Whether transmitted through sexual fluids, blood, the injection of drugs or from mother to child, the propagation of the virus depends on specific human behaviour. The virus does not "jump" on people. The specific behaviour may change from one society to another according to the sociocultural context, the state of politico-economic development and local circumstances. Identification of these societal components is, therefore, fundamental in understanding how and under which circumstances HIV/AIDS is spreading.

Once it has been admitted that the progression of the epidemic is strongly connected with the social and technical context in which human practices are rooted, sexual behaviour plays an essential role, even if other modes of transmission are too often forgotten or neglected. Little is said for instance about breast-feeding contamination which has now been definitely proved: in many developing countries there is still nothing done for the infected mothers giving birth, in terms of prevention policy, and recommendations remain elusive. A few years back, WHO recommended not to stop breast-feeding by the HIV-positive women in developing countries, a statement - more political than medical - which would have been unacceptable and would have created havoc if implemented in a developed country. Since a health system is a political system, we have to keep in mind that prevention policies are neither objective nor impartial. Different options are theoretically possible. In India there has been a combination of constraints and choices - both external and internal - to lay emphasis on fidelity, abstinence and in the last resort on the use of the condom, while elsewhere the objective has been to promote how to *enjoy* a safer sexuality, to promote alternative sexual practices. Sociocultural and economic factors influence these choices and constraints and can also be used as a justification, a pretext, to reinforce social disparities, gender inequality, group discrimination. Here arises the phenomenon of social re-appropriation: this means that a government, an institution, a local body or a particular group will take advantage of the outbreak of the epidemic to strengthen its position and pinpoint another group or certain individuals. In Africa for instance, it has been observed that in stratified societies the elders (seniors) who were losing their social power with the younger members (juniors) have managed, in the time of AIDS, to restore the traditional power relation, insofar as unmarried juniors were *assumed* to endanger society by having unsafe sex practices. In India, our research conducted among urban middle-class women has revealed that sexual discrimination was intensified towards those who were socially and spatially mobile. Women who tend to have other professional occupations than as housewives are more likely to become victims of stigmatization. Similarly, men accuse women of spreading the virus because of their inherent biological constitution: recalling that in the same way venereal diseases were previously called *pomballe seeku* (woman's disease) in Tamil society.

Regarding risk practices, it has become common to argue that the control of the epidemic will depend on the limitation or reorganization of these practices. The discovery of a new therapy now available in America and Western countries is like a miracle but, due to its incredibly high cost, and to the logistical organization that is required for regular drug provision for the patients, it will never be available or affordable for most of the infected persons in India, if we except a

handful of privileged persons from the upper classes. One has to remember that foreign pharmaceutical companies have hardly been interested in promoting cheap drugs for developing countries, and there is no sign which would indicate a change in the world economic policy in the time of the epidemic. And even if this were to happen one day, whether through a vaccine or an effective treatment, technical measures will never be sufficient to fight against the advance of the pandemic. This becomes particularly relevant in Asian and African countries where the public health delivery system is suffering from drawbacks, and where social and gender inequalities operate as constraints on the generalization of health care and on adequate and uniform access to it.

That is why social prevention is "condemned" as the main focus for any HIV/AIDS policy, even if every government has to encourage medical research adapted to its own capacities in relation to its economic, social and political characteristics. We must, however, explain what we mean by prevention. Is it just to make people aware of the disease, and tell them what to do, or what not to do? Social and individual prevention cannot be restricted to a mere communication process. In addition, there is the question as to whether the concept of prevention will be confined to its narrow definition, or extended to embrace a more holistic approach. For example, fighting against discrimination, encouraging adequate counselling and integrating HIV-positive persons into society can also be considered as further preventive measures.

While the identification of practices which are "at risk" is one aspect needed for the comprehension of the diffusion of the epidemic, we cannot reasonably make a pretense of taking on a complex problem just by touching it with the tips of our fingers. Practices are the consequences of existing structural and fluctuating situations, and the social dynamics that contribute to the spread of the epidemic must be discovered. We have to go to the roots, act as geologists and psychoanalysts, in order to demonstrate the need to focus project interventions in such a way as to take into consideration the socio-economic and cultural context which gives birth to the moment, place and conditions of vulnerability to HIV/AIDS. A concrete example taken from our research project will be discussed in the next session.

Various disciplines and bodies have been called upon to cooperate in the struggle against the epidemic and, as that is the purpose of this seminar, I would like to provide a few elements for reflection related to the human sciences and the participation of NGOs.

On the one hand, several contradictions are observed if we look into the mutual contributions of medical and social scientists. This is so, first, because AIDS is a challenge to biomedical science. Even if everybody agrees that the epidemic is related to society, development, culture and economy, there is an obvious attempt by the medical sector (specifically microbiologists in India) to control what is to be regarded as a social problem. This is not to blame doctors and other medical researchers. They have been the first to be confronted with infected patients, to realize the problem and the magnitude of the epidemic. It is human and justified on their part to try to counteract the disease. But improvisation can be worse than doing nothing. Because the situation was urgent, they were convinced that emergency solutions had to be adopted. I remember a well-intentioned doctor in Coimbatore who told me that if AIDS is spreading quickly, health planners have to act and change people's behaviour more quickly: a kind of race. The intimate certainty that there is no time to waste has led some medical personalities, along with paramedical staffs and social workers, to launch prevention projects without always being aware of the reality faced by the people, the day-to-day difficulties they

have to solve, their perceived priorities, and without recognizing the social contexts and circumstances liable to prevent the people from modifying their behaviour, in spite of a newly acquired awareness. Here, social scientists should have something to say. Their skill is supposed to enable them to provide a comprehensive understanding of social situations, to identify the dynamics of society, to design a cartography of the social structures in order to detect individual and group vulnerabilities regarding the HIV infection. Anthropologists, human geographers, and sociologists possess tools and adapted methodologies to analyze the facts and figures of a given society. They know that a society is not a mere addition of individuals, but is a living entity having its own rules which transcend individuals. A reality which is too often forgotten in many programmes, in which, I would dare to note, one will find a medical representation of the social: a preconceived idea is that individuals are negatively influenced by taboos, beliefs and superstitions which discredit prevention programmes. One has to overcome these "mentalities" in order to guarantee the success of the launched action. Another medical representation is the behavioural conception of human nature: human beings are perceived as rational and are supposed to act according to logical mechanisms. In other words, if new information is transmitted, then the person will grasp it, integrate it, digest it and change his behaviour accordingly. This false conception makes sense, however, for those whose intervention projects rely on the belief that by communicating a new message, people will operate differently if they receive the message in good will. Maybe it is necessary, but it is not sufficient. It means forgetting that human beings are made of flesh and blood, that they are unpredictable, changing and "irrational". As a counterpoint of this supposed mechanical behavioural attitude, one session will be devoted to explaining what specialists of human sciences mean by 'social', what the 'social' which they claim to study is, and what the specificity of social research can be when dealing with HIV/AIDS.

Furthermore, people live in a material and social environment which strongly determines their way of thinking. They already have their problems, and they do not have the same priorities as the developer and the policy-maker would like them to have. Coming to a slum in Chennai, one social researcher involved in my project arrived at the conclusion that people were more preoccupied by mosquitoes than HIV because they cannot sleep at night and children are badly affected by scratches. Even in the time of AIDS, and in spite of a generalization of awareness, the precariousness of living conditions appears to be a more important issue for the deprived population. Then, AIDS appears to be just one more killer disease among others. So, where must we start? Are we dealing with a disease or with a manifestation of underdevelopment and poverty? We will return to this point in a coming session.

Despite the theoretical recognition given them, it is surprising to observe that the social sciences do not benefit from this acknowledgment and, in reality, are not always welcome in the field of intervention. This is neither the place nor the moment to analyze the reasons behind this apparent paradox, but we may wonder whether government, private bodies and representatives of biomedical sectors made a judicious choice by avoiding social analysis under the pretext that there is no time, or that human scientists will only complicate the debate by hair-splitting. Action is important, but is it possible to economize on understanding before initiating an action? Despairingly, social scientists are in constant mourning. Their work is most of the time neglected, if not refused when it becomes too critical. All doctors will, however, agree that prevention is better than cure. Only when things do not improve and when projects are failing, are social

scientists called to the rescue; and the detractors realize *a posteriori* the potential relevance of their contribution.

On the other hand, the involvement of NGOs in the field of HIV/AIDS prevention and care is a direct consequence of the ethical necessity to *act* and approach various populations in order to create awareness, knowledge, empowerment, and to suggest that they modify practices, attitudes and modes of thinking that can lead to HIV exposure. Union and State governments, after a period of denial, are taking responsibility for the planning of different orientations of the national programme for the struggle against AIDS. But, respective of the nature of their official, administrative and national positions, they need more flexible bodies to extend, complete and implement the decisions coming from the "top". One assumption is that NGOs should be closer to the population, more aware of the existing realities and problems faced by groups and individuals. They can act as intercessors between government and the civil society and, by receiving feedback from what is going on in a particular area among a particular group of people, they are in a better position to adjust, innovate and create original solutions to interact with the people. Information collected from the "bottom" enables NGO activists to intercede and, if justified, call into question unrealistic targets and inadequate policy orientations. The question is not to know whether development has to start from the bottom (in the people's hands), or at the top (in the deciders' minds), as has been debated for years in most of the developing countries, but to find a compromise, a negotiation on the basis of the constraints with which government and people are confronted.

Of course, this remains purely theoretical because the majority of the NGOs are never completely free to act. They depend on funding, human resources and, frequently, underground connections; they can be submitted to political pressure whether at the national or international level, and sometimes they have to fit in a particular ideology if they want their proposal to get through. In fact, if we except a category of well-established associations having their network of support and a guarantee of a continuous financial flow, most of the others are living and working precariously. They are uncertain as to the possibility of continuing their project, and they thus have no choice but to proceed step by step, on a short-term basis. Such a situation influences their strategy and method of working.

Keeping those considerations in mind, the last session of the workshop, which has received the most attention in terms of proposed papers, will be devoted to identifying various strategies implemented by NGOs in the field of HIV/AIDS in particular, or in the broader context of development which includes HIV/AIDS as one of its components. The purpose here is less to describe the projects in detail than to try to bring out the difficulties found in their implementation, their replicability, to examine together the potential reasons for drawbacks. In fact, what is expected is more a critical and objective assessment than a mere promotion of achievements. We are not gathered to congratulate each other, to prove that we are right and that the neighbour is wrong. We do argue that it is more relevant and fruitful to question the work undertaken and evaluate what the judicious and preferable re-orientations should be, and of course what suggestions should be made, and to which extent these suggestions could be developed at the national level. Finally, the question is raised as to the position of the NGOs in a country like India. What is their influence? Are they bound to be confined to their area and work in isolation? Or are they, all together, capable of rectifying, if needed, the course of national policy?

We cannot expect linear propositions, definitive answers to these questions, but I do hope we will be able to lay foundations and contribute to reflection in that direction. Controversies and polemics are also expected. That is not to say we want a big fight and chaos made of the hall. No, we are just convinced that we have to submit our ideas to others and discuss them together. Polemic means to argue with reflection, after analysis, while personal problems between those present will have no opportunity to be heard during this seminar. I do hope you have come with this feeling in your mind, and once again, I welcome all of you.

NGOs' Involvement in Research and Action

Prof. S. Shanmunganandan, Madurai Kamaraj University, Department of Geography
(Tamil Nadu)

The idea of the workshop was initially mooted by the Indian Society for Environment with the view to discovering the gaps that exist in the system between the NGOs and government agencies. The realization of this idea has become possible with the National Agency for AIDS Research in France. One of the basic ideas was to generate a forum where NGOs could discuss their doubts, achievements and expectations. Nowadays in India, a great number of NGOs try to approach various sections of the society - specifically the weakest ones-, try to help people who are suffering from HIV and seek a way to resolve their problems by pointing out the discrepancies that exist in the social system. Actually, the Indian point of view is that there are various risks emerging both from our culture and from external influences which favour the outbreak of the HIV/AIDS epidemic in the country.

To counteract those risks, knowledge about AIDS, the proper understanding of AIDS, as well as change in the sexual behaviour have to be promoted. All this can be brought out by means of different strategies of AIDS awareness programmes. The drawback is that presently action projects do not comprise evaluation programmes. How far do the projects succeed in bridging the gaps prevailing in the population and in generating attitudinal changes? In fact, little is known about that. We may be led to error regarding the extent to which knowledge is diffused. People are today still unaware of AIDS in many parts of India, especially in rural areas.

It was in this light that the workshop was planned: what is the course of action of NGOs? In which direction do they have to move? How can they exhibit a coordinated effort along with the government agencies? NGOs may also face many problems in getting financial assistance, in finding logistical support from government agencies. The obvious reason is that government is not in a position to assume a uniform geographical coverage in the different regions, among the different target populations. This particular workshop was also planned to bring out the views of various NGOs as well as to acquire some understanding of their experiences. Experiences from the point of view of awareness programmes and, more importantly, from the difficulties faced. Only by knowing the practical and heterogenous problems NGOs are facing, can one be in a position to assess what could be innovative suggestions in implementing the programmes, as well as to readjust guidelines in a more adequate way.

NGOs and researchers are now at the crossroads: both of them know after having carried out many awareness programmes and having been in close touch with the local population, that discourse alone is not liable to bring about sustainable behavioural change among people. Immediate behavioural change and long-term behavioural modification are two major processes that are needed today in the absence of any treatment. Getting a clear understanding of the social dimension of the epidemic is therefore crucial for the design of the various aspects of HIV/AIDS prevention and control. In such a context, it is worth while to again emphasize what has already been pointed out: the urgent need to link the social action with research. It implies the involvement of social scientists as well as the acceptance of NGOs and government agencies to integrate research processes and research findings in their development programme. Last but not least, policy planners should induce a suitable environment to facilitate a more effective acquaintance between social scientists and people in action.

From my experience through the various studies I have carried out and read, I have come to know that people's perceptions and attitudes towards a proper understanding of then spreading of AIDS and modes of transmission, as well as other components of the required knowledge, have not yet been fully evaluated. In this respect, one must consider how NGOs should best take up this missing point, and what else they should do. It means not only creating awareness but also providing better care to the patients living with HIV and AIDs. NGOs may not be in a position to rediscover the socio-economic and cultural analyses which have been undertaken in previous research. Such additional scientific knowledge becomes therefore essential for all the NGOs.

Community care is only taking place slowly because of the high stigma attached to the suffering persons. Food system and alimentation is a potential component of HIV care which deserves to be explored. In India nutritional aspects of HIV infection are to be taken into consideration. The idea is that undernutrition and malnutrition have some influences in the evolution of opportunistic disease and may accelerate the passage from HIV to AIDS. The Indian Society for Environmental Health (ISEH) is investigating that area. We have introduced programmes and carried out studies to discover the traces of nutritive elements in the bodies of infected persons. The purpose is to know whether nutritional components (combined or isolated) influence positively or negatively the infectious state. In other words, the assumption is that some nutritional components may be delaying the progression of the disease in the body. A conference was held partly on this topic in southern France some years ago (1994). Then, a second conference on HIV infection and nutrition therapy was conducted last year in India. A complete lack of knowledge in terms of potential nutritional relationships with disease evolution as to be observed among the NGOs. Further emphasis in the seminar was to increase their awareness of this factor. Sensibilizing the government officials was also crucial. It is essential that suitable programmes on nutritional intervention therapy receive more attention as the number of AIDS case is increasing daily, and because we know that no affordable allopathic drug treatment will be available for everybody in India. The country has therefore to look for alternative and realistic solutions.

NGOs are also conducting systematic awareness programmes in order to explain the epidemiology, the modes of transmission and control and the necessity to modify unsafe sexual behaviour. NGOs give advice regarding how to bring about a change in lifestyles, how to generate behavioural change. But once again, planners and NGOs have failed to evaluate, or failed to collect, the relevance of the information networking system. More research trainers are needed. In India, the heterosexual mode of transmission assumes the higher percentage (80%) among the total modes of infection. Emphasis should be focusing on strategies to modify behaviour and to make acceptable the use of condoms. What is the rate of condom use among commercial sex workers? To which extent do commercial sex workers insist among that clients wear condoms? Numerous studies detect tremendous disparities between the awareness dissemination strategies and the effective acceptance to use condoms. Many other reasons are interconnected: some will argue that they lose their sexual feelings, others that they do not know how to put on a condom, others that it is not something virile, etc. Being closer to the people, the role of the NGOs is more important than that of government agencies: the former have better and easier access, better commitment than the government and bureaucratic agencies.

The governmental institutions try as well to introduce the national programme through the NGOs, which are more flexible bodies and which are supposed to be more knowledgeable regarding the Indian pattern of health care system prevailing in a particular place. Without the support of the NGOs, a national programme can hardly be successful. But, at the same time, the

NGOs should be encouraged to have better access to resources and to the utilization of the funds with a minimum of administrative barriers and control. Of course, the funds allotted should reach the people and a kind of control is needed.

Another aspect is the involvement of the people in the planning process. How do programmes manage to mobilize people? Whenever NGOs implement their programmes, they should first identify the general pattern of the population, then some sub-groups, then some key persons liable to bring out the dynamics of change. These different levels of population identification are still lacking at present in the Indian setting. Identification of leaders among the vulnerable population is required if the developers want the planning to reach the whole population. It may bring about some amount of success, even if not sufficient in itself. Definitely, the responsibility of the people, the responsibility of the community, the responsibility of the NGOs should be clearly defined.

The superposition of private associations should deserve attention. It has become a typical feature in India (specifically in Tamil Nadu) that whenever two or more NGOs act in a particular area, they cross each other, introduce similar programmes without consulting each other and without bothering about the confusion which may be created among the targeted people. Such a situation is exacerbated by the different nature of the messages they provide according to their heterogeneous ideologies: one NGO is providing awareness by promoting condoms while the other does not talk about this method of prevention. Conversely, sharing the same geographical regions and targeting different groups (through various NGOs) may yield good results if the organizations work in synergy rather than simply repeating programmes, or acting in contradiction.

For this purpose, NGOs should have national and local networks which would enable them to identify the geographical regions, the areas of research undertaken in a given place. India being the second most populated country in the world, it is very difficult, if not impossible, to conduct any national programme which reaches the entire population. The number of NGOs is increasing drastically, but if we have in mind the number of NGOs in relation to the total population of the country, the number is insignificant. In some states like Bihar, NGOs are virtually absent, also in the field of HIV/AIDS. Even in some remote parts of Tamil cities, there are no NGOs actively present. The spatial distribution of NGOs is not balanced. The geographical disparity dimension must be taken into account: national agencies should favour the implementation of NGOs in new areas. Given the prevailing condition, the establishing of a network among NGOs is essential. Perhaps the workshop will come up with innovative findings and conclusions regarding such networking aspects. In that case, a notice could be passed to the government as well as to the policy planners in order to induce a protocol of proper articulation between the NGOs and the governmental agencies.

Discussions

Usha Raghavan : It is quite interesting to talk about the networking and the spatial distribution of NGOs in particular geographical areas. But, having experience with NGOs for the past 5 years

at the Tamilnadu State Aids Control Society³, I observe that networking is still a project in India, and that Tamilnadu is ironically supposed to be a model for the other states in the country. At the grass root level nothing is done. I would say that networking is the major drawback among the NGOs. I don't know the reason behind this. It must be a combination of competition, suspicion, struggle for prestige. Every day there are new NGOs emerging or trying to establish themselves. According to their requirements, there is not place for everybody, at least in terms of finance availability. Another criticism is that most of the NGOs absolutely avoid the research dimension. This being the case, without having even a basic knowledge of people's day-to-day life, how can they implement any proper project? The importance of social science research is known to the social scientists but insufficiently to the non-specialists. Until NGOs undertake some baseline survey, they cannot identify where the sex workers are, where the target area is going to be, in which field they have to concentrate. I am not blaming the NGOs involved in the area of HIV/AIDS. The sad fact is that there is no provision at all for the research. Donors do not encourage the research aspect. They expect targets and achievements and want the NGOs to provide clear reports which show an increasing number of condoms distributed, and so on. On the other side, the scientific medical research is given priority. It is legitimate to try to discover a new medicine or vaccine. But even if that were to be successful, social research cannot be avoided. In terms of prevention, if there is no behaviour modification, the situation will get epidemiologically worse and worse. That is why baseline surveys have to be given importance by the international agencies as well as by the government.

Prof. Gurumurthy : I am an anthropologist from Dharward University in Karnataka. I disagree with Usha Raghavan because the NGOs have to do certain type of work. It is the job of the social scientists to conduct the research and then to keep the findings ready and available. Social scientists have to work no doubt in collaboration, but if the NGOs begin concentrating on the research aspect, it may be difficult for them because there are few people, meagre funds and little time to cover all this set of activities. The solution would be that NGOs should work hand-in-hand with social science agencies. The combination would generate a synergy liable to improve the action-oriented work.

Usha Raghavan : That is what I mean. I didn't say only NGOs should take up the research. When they want to realize baseline survey, the funding agencies should appoint the research agency for a collaboration. I am not saying NGOs can do it alone. NGOs are not in a position to take up the research because the time allotted to them is also limited and they do not have the provision for employing a social scientist. In Tamilnadu, the funding agencies which are to pass via the government, or more precisely a semi-government apex (TNSAC), have to take the responsibility and to make available some provision for the development of social science research. International agendas must proceed in that way. So it is not the NGOs fault.

Prof. Gurumurthy : It is presumed that NGOs will start to implement their projects only after knowing what the problem is, where the problem lies, and how to deal with it. Unless they are in possession of a minimum of tools and knowledge, for instance the meaning of the social, I do not think that NGOs will rush to do something by themselves.

K. Santosh : While implementing the National AIDS Control Programme, the government of India have given no importance to social scientists. No creation of social scientific posts for the programme has been enjoined. Consequently, Indian deciders have left aside the social aspect of the epidemic. It is a pity because the country could have benefited from the experiences in Africa and in Europe. But this has not been the case at all. Similar errors have been made, I would say, knowingly. The social dimension was perceived as something of secondary importance. They have given priority to medical and technical personel. For that reason, what Usha Raghavan said is correct but insufficient. It is a structural problem. The biomedical establishment deliberately tries to manage the epidemic. There is no scarcity of social scientists : they are not supposed to be a part of the people involved in the struggle against HIV/AIDS.

Prof. Gurumurthy : There are national level research agencies like the Indian Council of Social Science (ICSSR) and many other university research centres. then there are a lot of independant research centres like the ICLAC. Each one of them is doing a lot of work on HIV/AIDS. But there is neither coordination nor cooperation between the agencies themselves. Worst, there is poor collaboration with administrators and people in action. Everybody is still working as a different, autonomous and isolated entity.

K. Santosh : Maybe. But regarding the case of the funding constraints outlined by Usha Raghavan, the international agencies and to a lesser extent the local governments (i.e. state) are nowadays the main sources of income for the NGOs. Because of the externalisation of the funding, local Universities are poorly encouraged to establish some durable networks with NGOs. Unlike NGOs, universities - for some administrative, logistical and legal reasons - are in a difficult position to receive funds from the World Bank, the European Community, the United Nations and any outsiders.

³ The official semi-private body in charge of the prevention programmes in Tamil Nadu.

Paradoxically, the research is separated from its original place, where it is supposed to be taught. It generates opportunity for private-oriented marketing research centres to endorse the research activities. The question is whether it is advisable to associate business with research activities.

F. Bourdier : To sum up schematically, we may say that the private sector receives, but not exclusively, much more material support than the public sector, including universities and other government research institutions. Institutional research bodies, except a few like the Tata Institute of Social Science in Mumbai (a private body sponsored by the Tata group), are poorly encouraged by donors to improve their skills by receiving, for instance, an additional teaching curriculum, scholarships for PhD students, and money packages to launch research programmes. On the one side, foreign agencies are reluctant to face the Indian administration which systematically entails time delay, money retrocession and, worst of all for some international donors which are a part of the globalization process, potential control by the Indian Government over their activity. On the other side, human resources are under-utilized or, more precisely, selectively utilized, because priority is given to private persons irrespective of their background. Some of these private persons benefit the system because they have been able to establish underground social networks, political ties, economic acquaintances, friendships, if not allegiance, clientelism. In Chennai for instance, there are NGOs run by influential politicians and their relatives, by retired Indian Administrative Officers (IAS). Such groups of people know how to get money either from abroad or from within the country. They are empowered to get both public and private money. Personal motivation and research capacities are merely secondary factors for their involvement. It creates a gap between academic research undertaken in colleges, government institutions and people who become - sometimes artificially, sometimes because of opportunity - involved in research action and who are not necessarily in possession of sufficient tools and knowledge from a given social discipline. Frustration turning to jealousy is a direct consequence of unequal distributions of assets. The purpose should be not to favour either one or the other sector, but to mobilize and utilize all the available human resources.

Prof. Gurumurthy : I realize that we have come back, with detailed clarifications, to what I suggested earlier. That is, that the NGOs should get together, interact and present the problems that they face to social scientists. NGOs are in constant and close contact with the population. It allows them to have pragmatic experience of the quality of interaction occurring within the community. Scientists can orient them, provide methodological issues and new ideas. I do hope these points will be adequately recognized and discussed in the coming days.

S. Surender : I belong to the International Institute of Population Studies (IIPS) in Mumbai. We are academicians but we have experience in collaborating with NGOs. The basic problem with the NGOs/social scientist relation is that we, social scientists, are not able to identify the evaluation at the outset. To start with, most of the intervention programmes are accepted for evaluation after the intervention. Evaluation is not thought about in the initial stage. Once the intervention is finally over, the developers engage researchers like us. No baseline survey data is available. So we have to come up with some findings, depending upon which funding agency has asked for our services at a given time. Most probably, the hidden agenda is that we cannot say no to an intervention which is providing ultimately an unsolved problem. Nor are we in a position to decide when the evaluation should be undertaken. In our view, it should be thought of at the beginning of the intervention stage itself. Evaluation done only at the conclusion of the intervention may not be useful for further research.

B. Shanmunganandam : I do not agree. The evaluation process can be carried out after implementation. Some modifications can be done when we plan for the future implementation. Once NGOs have conducted their awareness programmes, the discrepancies can be easily found out. With ISEH for instance, after the presentation of the awareness programme, we would conduct pre-evaluation and post-evaluation tests in order to know what amount of knowledge is available for an individual who is potentially exposed to AIDS information. After carrying out the awareness programmes, we undertake a post-evaluation. This is where we must find out who are the people and who are the groups that are not able to receive the information and to detect the points which are misunderstood. It may involve many instructions regarding the regional languages and social conditions of the people. Sometimes many diagrams, figures, videos, movies, slides used as visual explanation for the people have to be changed. It is important to know this in the sense that at present people get a lot of awareness messages because of the increasing development of audio-visual techniques related to AIDS. But audio alone cannot help people, because they sometimes just listen. It may be just to pass the time, like going to the cinema. It does not mean that they understand and will behave consequently. This is why we have carried out studies in Madurai City in order to learn about the feed-back to our programme interventions.

F. Bourdier : Superficial analysis leads only to superficial statements. I do agree that it is important, legitimate and necessary to know what the people know and think about AIDS, sexually transmitted diseases, reproductive health and so on. But it is far from sufficient. The pre-evaluation and post-evaluation assessments you are talking about are based on individual statements influenced by psychologists' theories. Numerous studies all over the world have definitely proved that one cannot change individual behaviour without taking into account the sociocultural, and politico-

economic conditions which give birth to them. Behavioural studies based on a mechanical perception of human decision do not provide a clear picture of the social reality that individuals and groups are perceiving. The second critical point is that even if one is aware of the danger of the epidemic, it does not mean that one will behave in a rational way in order to avoid this danger. In other words, there is no direct correlation between knowledge and behaviour. The third point is that rather than blaming the people of having misconceptions, false reasonings and a poor ability to understand, it would be more judicious to have a clear understanding of the socio-economical and cultural dynamics in which they are involved and which may act as constraints, and therefore to try understand their world through their own categories of thinking.

Child Abuse and Prostitution in Tamil Nadu

Mrs. S. Usha, Women AIDS Action Development Society, Trichy (Tamil Nadu) Representative for the National Committee for Women in India

Indian society is composed of more than nine hundred million people. Since the outbreak of the epidemic, the so-called commercial sex workers have been the scapegoats and are accused of being responsible for the growth of the epidemic, to be the vector of the virus. It is a facile statement which prevents the rest of society from being accused, if we except a few other targeted groups such as truck drivers and homosexuals.

In reality, if some women in prostitution are infected, and it is a matter of fact, one has to remember that they did not get the virus from the sky. Men gave it to them. It could have been a Minister, or a rich industrialist, a respectable father from a typical middle-class family, a mill worker, a land-owner, a rickshaw driver.

The men come to see a prostitute by choice; the women receive them most of the time by constraint. The former did not bring condoms with them, and if it was proposed by the women, men have refused in many cases.

When speaking about the question of prostitution, NGOs, government and social workers have to consider different contexts. It is also surprising that while women in prostitution are in a situation of vulnerability and consequently are the first persons in danger, they are considered dangerous by society and are, therefore, also neglected.

An illustration of this social and individual vulnerability to HIV/AIDS may be given by focusing on children entering into prostitution.

There are about 400,000 to 500,000 child prostitutes (boys and girls) in India, according to a survey done by *India Today* magazine. Research suggests that such exploitation is growing, and that the age of children involved is falling.

Most children in the sex industry are girls between 13 and 18 years. Many such children spend most of their lives on the street, often because they are escaping violence or sexual abuse at home. Other children live in brothels, having been brought into them by procurers.

The physical and mental abuse of children may increase the likelihood of their engaging in risk-taking sexual behaviour and thus increase their vulnerability to HIV.

The HIV/AIDS epidemic has made child sexual abuse and abuse of children within prostitution more dangerous than ever before.

Studies everywhere indicate that rates of HIV infection among children involved in the sex trade and street children are often very high.

The belief that children are less likely to be infected has raised the demand for younger sex workers in recent years. The vulnerability of children to sexual exploitation, either through sex work or abuse, may well result in their becoming infected with other sexually transmitted diseases such as gonorrhoea, syphilis and chancroid. By damaging the surfaces of the reproductive tract, physical trauma and sexually transmitted disease each increase the child's susceptibility to HIV, as well as the risk to their clients.

The National Commission for Women is taking steps to tackle the problem of child abuse and prostitution, insofar as it has not been debated and taken practically into consideration. The National Commission for Women recognizes that community organizations of women in prostitution can be the most effective agents towards combating the abuse of children within prostitution.

First it undertook comprehensive research to have a clear picture of the sociocultural situation. Through our own investigations with over 200 women in Tamil Nadu, several of whom have been working in prostitution from a very young age, the National Commission is in a position to point out some facts which NGOs, government agencies, activists and planners sometimes ignore.

It is a myth that poverty alone is the reason for children entering prostitution. The absence of "safe" and "secure" relationships within the family/community which sustain the turbulent passage through adolescence, compounded by poverty, lack of marketable skills for gainful employment and rising aspirations, fuelled by a rampantly consumerist society, are increasingly encouraging children to leave their homes.

Most young women entering prostitution are from rural areas. They come from interior villages surrounding main cities and towns.

It is a myth that education is the key to this problem. A significant proportion of the minor girls met had studied up to the secondary level. However, they had no skills that would get them a job.

It is a myth that all families are loving and caring and that parents automatically take responsibility for the children they bear.

A surprisingly high number of girl children are sexually abused within the family. This often forces them to leave home and seek shelters that do not exist. Instead, they get drawn into the vortex that is prostitution.

It is a myth that society and its welfare structures really care about the child abused within prostitution. Till today, no structures exist that can care for her emotional and physical well-being and rehabilitation.

It is a myth that all children are equal in the eyes of the law and have the same rights.

While activists clamour about the sexual abuse of children outside prostitution, not a whimper is heard regarding the continuous rape of children within prostitution. Instead, society and law enforcers go so far as to label them offenders under the law.

Despite the so-called "efforts" of a "concerned" police system, there was a 60 per cent increase in the number of rapes of girl children and a 100 per cent increase in the numbers involved in prostitution between 1990-94.

The National Commission for Women recognizes that these myths have to be directly confronted before specific courses of action can be considered.

The National Commission for Women experiences the life of women and children in prostitution as a reflection of the continuum of societal oppression and bias against girl children and women in general.

However, the physical and sexual abuse of children is experienced in its most extreme form within prostitution, through the confinement and rape of girls and young women.

The National Commission for Women further recognizes the vulnerability of the girls/ young women in the context of rapidly rising rates of HIV infection. It wishes to place this concern firmly in the context of any discussion regarding the abuse of children.

The National Commission for Women affirms all the resolutions adopted by the UN declaration on the rights of the child; in particular, that the State shall protect children from physical or mental harm and neglect, including sexual abuse or exploitation.

The National Commission for Women commits itself to facilitating effective implementation of these rights and recommends that these be anchored firmly in all development plans and policies of the country.

The National Commission for Women recognizes the need for enlightened and socially relevant legal rectification of the prevention of physical and sexual abuse and rape of children for a lasting solution.

It recognizes the need for concerted efforts by NGOs, community-based organizations, governments and other agencies towards this end. This concerted effort is absent at present. And we are wondering why the law is not respected, why NGOs are not approaching this problem directly, why there is no attempt to focus on the family context (which seems to be the key to understanding), why women in prostitution are targeted and not perceived as victims.

The National Commission for Women recognizes the role and value of the collectivization of women in prostitution as an important step towards dealing with the issue of confinement and rape of girl children.

Finally, the National Commission for Women pledges to effectively and realistically address the well-being of these children and commits itself to the political will necessary to create a better environment for all the children of our nation. Institutional and government responses are very low, if not absent or ill-oriented.

No institution has any programmes specifically aimed at preventing the sexual abuse of girl children and their entry into prostitution.

No specific effort is made to verify the ages of the girl children, and if arrested and sentenced to remand, they are all detained in the government vigilance homes along with adult women.

No specific effort is being made to reach girl children within prostitution, either for their education, rescue or rehabilitation.

No attempt is made by any agency to specifically focus on girl children, their shelter, education, vocational training, counselling, etc.

No institution is actively concerned about preventing the entry of girl children into prostitution. Instead, all efforts are aimed at rescue and rehabilitation, even though they are not specifically focused upon children and are directed towards women in general.

There are no counselling activities, with adequate resource persons, available for victims of sexual abuse anywhere in the State.

Consequently, there is an urgent need to take all these points into consideration, as well as to change the preconceived ideas which are rampant in both NGOs and government implementation projects.

Discussions

Dr. Abdoul Amide : You have presented an unusual paper and a few points deserve to be clarified. One of the factors which has led to people - either children, women or men - being driven into prostitution is their lack of marketable skills. This is a point which NGOs can take up. Among the people involved in prostitution, they could impart to those who are liable to be rescued some marketable skills. Take the example of leprosy. There was a social stigma attached to the disease. A long time back, an institution was created in Pondicherry where people were taught skills like making baskets and handmade paper, printing and binding. How many of the commercial sex workers will be willing to learn a new skill, and to which extent can this skill satisfy them in terms of money opportunity and interest: these are questions that you have raised, with misgiving, in your paper. Since we are always talking about awareness and the use of condoms, we should somehow concentrate on the roots of the problem: how to divert them from the profession? NGOs should have a more integrated approach and should be in touch with some other NGOs working in the development field. Job empowerment is essential. Because one may presume that people in prostitution are neither involved by choice nor because it provides job satisfaction. How many of them will be willing to give up prostitution if offered an alternative employment? Social scientist should think about this.

F. Bourdier : As social scientists we are not supposed to make any judgement about anybody. As you say, those willing to be rehabilitated may be encouraged, and one has to undergo the feasibility and the acceptability of a sustainable rehabilitation. But how and under which conditions? Frequently, rehabilitation programmes in Tamil Nadu are hardly acceptable for the women. One has to see what it is going on in the government vigilance homes and in the rescue homes which are supposed to generate new inclinations, to provide a new social environment. In fact they are functioning as mere jails. Discrimination and disdain are common features. Worse, it happens that some brokers (i.e. people who act as intercessors and who engage the others in organized prostitution) use the centres to identify new attractive and vulnerable women. Further more, in the so-called rehabilitation programmes the women are taught old fashioned skills like thread making and puppet decorating. One cannot call those activities "skills". Consequently, most of the women try their best to avoid such a static situation and manage to run away as soon as they can. On the contrary, women should have the possibility to decide what skill is going to be helpful for them in the future. In that respect, researchers may look into the acceptability and the feasibility of such social projects by designing a social cartography of the constraints and choices faced by the persons.

Carlos Sequeira : I am from Freedom Foundation. In Bangalore we are in touch with destitute women and most of them come voluntarily to our centre. Those who are HIV positive may use our facilities and we do our best to take care of these women by providing psychological support, food, shelter, basic cure for minor ailments. Most of the time, these women are alone in life. We intercede with the government and public services. But

from the government side, building capacity resources are not taken into consideration. Many times I have been to the office of the Karnataka director in order to ask her to take the responsibility for those that we are not able to keep, either for severe medical reasons, lack of place or insufficient money. The lady officer used to refuse to send the girls who are HIV positive to any public institution. The director usually calls the families of the seropositive children or seropositive women and tries to convince the relatives to take care of their daughters, without telling them about their seropositivity. What happens is that most of the girls are terrified to go back to their families. One of the main reasons is that these girls once have been sold by their own parents and if they come back, they are afraid to be sold again. Administrators have absolutely no idea of what is going to happen to the girls that they try to rescue without having conducted proper inquiries into their family environment. The second fact is that they do not know how to deal with HIV-positive people. Maybe because there are no legal provisions, or simply because they are unconsciously discriminating against the infected persons. Then, quite a number of orphaned girls are still locked up just because they are HIV positive. Not because they have done something wrong: just because they have been tested positive, mostly through mandatory testing. Our association is looking up the various ways to pressure the government to release these girls. Freedom Foundation is an organization which is more and more focusing on the rights of positive people and of child prostitutes. Definitely, a close relation with S.Usha and the National Committee for Women may stimulate new insights.

Prof. Gurumurthy : Your assessment has to be commented upon. Mr Sequeira first mentioned that child prostitutes were sold by their parents. I would like to know how for sure he can assess if they have effectively been sold by their father or mother. It is not a particular theory, but no parent from my experiences with devadasi-s (i.e. god prostitutes) would do this. Neither parent nor kinship by blood will do this. The family may be cheated. In that case, without their knowledge their girls may be sent to brothels. The family will be assured that their daughter will get a god and lucrative job. The only situation in which it may occur is when there are adoptions. In some families, children are given, exchanged, sold and taken from the family. In that case, if somebody claims a few years after "this is your child, come and take her", it will not have any effect.

Dr Venkatesvaralou : I would like to make another clarification. Mr Sequeira mentioned that parents sold their children who then are turned into forced prostitution. The abandoned or kidnapped children were taken from the family; but afterwards these children can get financial help from the person who employs them or bought them. I don't think you do have figures and facts to verify and to prove such statements.

Prof. Gurumurthy : Let us go back to Mrs Usha's paper. Mrs Usha was just mentioning that women in prostitution were not having a skill, a commercially viable skill. Let me draw attention to the fact that in the Indian caste society, each caste has its own traditional occupation. Today in rural areas some of these occupations are lost, like the basket makers, the pot makers and many other crafts. Villages have lost their weavers, because in the city the factories provide cheap durable aluminium vessels that are available and affordable to everybody. Nobody bothers to buy pots except for decorative purposes. It is the same with the basket makers and with the weavers and leather workers. So NGOs want to give the so called destitute ladies some skill, only after they have become prostitutes. It can be too late. Ex-prostitutes usually are haunted to be brought into some institutions. As an anthropologist, I am sensitive to what is known as culturally and psychologically compatible in that domain. If I want to give work to somebody, the work issued should be logically and culturally adapted. For example, if I ask landless low-caste labourers to keep a cow and then to sell milk, they will not do that because socially and culturally they are not accustomed to doing that; instead, if you ask them to keep poultry, they may accept and do well. Reciprocally, upper-caste people may not keep poultry as far as they are vegetarian and, consequently, are not psychologically prepared to rearing chickens or any type of domestic animals. NGOs have to take into consideration what we anthropologists call "culture". Unless developers look for what can be culturally compatible, the people will not accept what will be perceived as a constraint for them.

Dr S. Subramaniam : Congratulations Mrs Usha on your presentation. I happen to belong to another NGO that deals with girls caught, sentenced and released under the Immoral Traffic Act (ITA). My organization takes care of these ladies who have been abused either by their family, husband, friends or peers. The staff members take them and train them in rehabilitation skills. We have had some measure of success in getting some of them back to their husbands and back to their homes without lasting conflict. At the present moment, the strength is about seventy and there are four children in this group born of these girls. ISEH conducted a survey regarding their HIV status. We found that four out of them were HIV positive. It is a lot, but at the same time we were happy about the result because we feared it would have been much more.

G. Gunavathy : Regarding what Sequeira said, not only in Bangalore, also in Tamil Nadu, ladies were rescued from brothels. After one year a survey was undertaken by some Tamil magazines about their present status. They found that again most of the ladies have disappeared and /or gone

back to their old profession. The problem is that the attitude of society has not changed. To provide them with a new life is not sufficient. Society has to accept them, or at least to forget the past. But this never happens. Even if you ask some people to keep an abused woman as a housemaid, there are chances that they will not accept, because of the stigma, and because of the potential influence she may have on children, etc. In fact, society cannot help itself from being afraid of her. The attitude of society is such that situations of vulnerability have poor chances to be modified, whatever NGOs or the government have done to rescue them. I don't know how far rehabilitation is going to be helpful on a long-term basis. The second aspect which was pointed out by Mrs Usha was that sexual exploitation within the family is high in Tamil Nadu. Compared to other states in India, random surveys by the National Family Health survey show that 50% of the marriages in Tamil Nadu take place within the circle of relatives. This is a very specific pattern of Dravidian kinship which explains the very high rate of cross-cousin marriage and maternal uncle/niece alliance in Tamil Nadu. Sexual abuses within the family are frequently reported: the potential traditional right to marry one's female cross-cousin for instance, allows men to take advantage of this prerogative. It is a major fact in Tamil Nadu and we hardly speak about this. We cannot easily tackle the problem of getting married within the circle of relatives because it has certain advantages in terms of dowry, land inheritance, property rights, social acceptability. But the age at marriage among the girls who get married with a close relative is generally very low. Biological disadvantages are very high and this social situation increases individual vulnerability. It happens that many girls cannot bear this situation, and one of the extreme solutions is to runaway which, conversly, makes them vulnerable to being driven into prostitution. Available figures tend to demonstrate that sexual exploitation within the family is higher in Tamil Nadu than in any other state; but in Bihar and Uttar Pradesh I have been told that various kinds of incest - that is between parallel cousins or between persons from the same gotra (clan) - frequently occur. It is a very sensitive issue in a country like India because the family is idealized. However, the problem finds its roots in the family system which is no longer adequate to the contemporary way of living. y words are just an example to show that superficial approaches will cure the symptoms but not the disease.

Male respondent : Why has S.Usha, who is a member of a women's committee, stated that men infect women. Cannot it be the contrary?

S. Usha : I will not accept that. As far as AIDS is concerned, men pass it on to women. Please bear that in mind. We live in a patriarchal society where man alone makes decisions in sexual affairs.

Male respondent : But from where did men get HIV/AIDS then?

S. Usha : Homosexuals, why not?

Dr. Venkatesvaralou : Another pitible dimension is the poor innocent housewife who has not committed any crime, except being with her husband who had himself been infected by somebody else.

F. Bourdier : You speak about "innocent" women. This means that there are other women who are not innocent. If we start to wonder whether this one is a victim or that one a culprit, we are going to judge the whole society which is meaningless and goes against any prevention efforts. Morality has no place when dealing wiyh care. Regarding the epidemic, everyone has to be considered as a victim. What is the use, in terms of individual and collective prevention, of making this artificial distinction? One has to remember that discrimination starts at that level whenever a society tries to find scapegoats. It is recognized that such discrimination will in turn mitigate the preventive measures undertaken by NGOs. If someone has a car accident, the witnesses will call for an ambulance: there will be no question of inquiring before whether the injured persons were driving carefully or not. In the same way, when dealing with HIV/AIDS, everybody has the right to receive affection and to be rescued. Every accusation is a social reappropriation, insofar as some social groups may have an interest in accusing others. Not only in terms of social justice and ethics but in terms of personal and civic responsibility, we have to be aware of the permanent danger that gives way to voluntary or involuntary stigmatization.

Dr V. Jeysingh : From my experience of working with the sex workers in Belgaum and Dharward in Karnataka, I have been stuck that most of the time the same person is arrested and released. We know that in Karnataka, every week (Friday) policemen are supposed to book a certain number of cases. Ladies in prostitution are aware of this, and feel safer staying at home on that particular day. If one is a poor cycle rickshaw man without light on his vehicle, the policeman will catch him, because he has to book a certain number of cases per week. In the same way, the police will go to the brothel and say to brothel keepers "Give me three names". Usually in the brothels, the owner will give three names of girls who are either

menstruating, not keeping well or are affected by a sexually transmitted disease. Afterwards, at government expense, the girls who are caught will be removed from the brothel and put in a state home for women. They will be kept there from three to six days and then released. Some prostitutes are treated like this regularly. You can easily imagine the psychological state of mind they develop. I don't know whether they are given any medical care and to what extent the overpopulation is the cause of any absence of legal procedures, before the judge pronounces any judgment. The magistrate will ask the jailer or the person in charge of the state home for women, "Do you have space for four more women? (...) because I am sending other persons". If the answer is negative, the judge will immediately charge a symbolic fine and release them. There are many discriminating factors responsible for the social vulnerability of the ladies.

David Thiagarajan : I am from IMAGE, a NGO based in Madurai. One can observe a similar process in this city in Tamil Nadu. Sometimes, there are some "professional" ladies who have a commitment to both the local police and the brothel owners. They accept, against a reasonable tip, to be officially taken to the police station where a file will be opened. In fact, they believe that there will be no long-term implications because they will be freed just after their deposition. Then they will probably be voluntarily taken again a few weeks later. There will be a rotation between girls who are part of the game. It would be an error to perceive police, brothel owners, pimps, brokers and girls as different entities. It is like a kinship with its own network, affiliation and shared benefits. Although, the ladies are of course more victimized.

K. Santosh : Mrs S. Usha was very particular about the designation: What should ladies who sell their bodies be called? From my past experience while working with various NGOs before shifting to research, the women were referred to as commercial sex workers because they sell their body for money. If we follow this logic, every one is selling his or her profession for money. A doctor sells his medical advice for money; a lawyer sells his knowledge of law in the same way. But nobody says that a doctor is selling a treatment. Why then we denote only the sex workers as *commercial* sex workers? They have only their body to earn a livelihood. So they sell. Usha and her fellows objected at the National Commission to the use of the term CSW because it is full of ambiguity. We rather say "women in prostitution", mainly because most of the ladies are not only working as prostitutes, and because it is not a choice. Some have a respected permanent job, others are housewives, others are only occasionally involved in the sex trade. The fact is that in Tamil Nadu women themselves reject the terms prostitute and CSW.

Ramkumar : I am a student in psychology, coordinator and field worker for a NGO in Pondicherry. The terminology of prostitution has changed into commercial sex work. Let it be. But if the Indian Commission on Women's Right (ICWR) recommended another change, it has been rejected by the government. The word prostitution seems to carry a stigma. The ICWR makes the designation " women into prostitution " a more dignified term than the word prostitute. Nowadays, the latter is internationally accepted and all journals employ mostly the term commercial sex workers. It is confusing and a waste of time. I don't think ICWR is competent to lobby for changing things like that. We may wonder whether the concerned ladies think the word prostitution is more respectable than commercial sex workers. But personally, I fully disagree with this. I would like as well to tell you something that happened in Pondicherry. A good looking girl was in the profession for about three to four years. A policeman along with another home guard happened to meet her regularly. This happened four or five times. Both of them had sex with her. One day she was arrested by the same policeman. Then after a mandatory testing, she came to know she was HIV positive. She was cast off by the brothel she was attached to, rejected by her fellows and by everybody who knew her. Then, she thought of voluntarily infecting men, specially the policeman who used to force her without using a condom. She wanted a sort of psychological revenge : "Society has given to me, I have to give back". This sad anecdote is not isolated. It has also happened in other places.

G. Geetha : What did you do afterwards ?

Ramkumar : Our association not only counselled her, but advised her that ultimately she will not earn any lasting satisfaction out of her primary reaction, that the customers who come to her afterwards are not involved in her past story.

Prof. Gurumurthy : Speaking about prostitution, a clear distinction should be traced out: the common prostitutes and the sacred prostitutes, also called devadasi-s. You have to differentiate between these two categories because the context and the implication differ. In some countries, prostitution is legalized and licenses are given. In those countries, when we use a particular word, it gives a different meaning in terms of acceptance, law and - to some extent - integration. Then you have to explain what you mean when using the word commercial sex worker in a particular context.

The problem with India is that no licenses are allotted to ladies in prostitution in spite of a few social movements which emerge sporadically in Calcutta.

F. Bourdier : In fact, the need for an alternative designation has been decided by the representatives of the women in prostitution. They had named themselves as women in prostitution. Who are we to decide on their part the relevance of this or that? They have decided. They have a National Commission for Women which ratified it, that is all. They fight for their fellows and they have the right and the duty to do that. That is what S. Usha tried to explain to us. As Prof. Gurumurthy said, situations may change in India. But we cannot interpret the recent and ongoing movements as minor events. For instance, Durbar Mahila Samanwaya Committee is a forum of 30 000 sex workers from different red-light areas in West Bengal. The organization has a strong network among sex workers and is fighting against injustice, exploitation, oppression and for solutions to their day-to-day problems. In November 1997 (a few days after our seminar), they are organizing a National Conference on sex workers at Calcutta. The central theme of the programme is about workers' rights. Inspired by the success of their action, they are organizing in March 1998 another meeting. But on a regular basis, they struggle against the precariousness of their life and try their best to make a cross-section of people aware of their problems and disseminate their issues to people in general: they are conducting opinion polls on workers' rights for sex workers throughout Bengal, street cornerings, organizing interactive sessions with political parties, trade unions, NGOs, women's organizations, intellectuals and media. One of their aims is the legal recognition of the sex trade as an occupation, the existence of a self-regulatory board, a demand for worker's rights, the prevention of entry of minor girls into the profession and human rights.

S. Usha : Being a representative of the Women's Organization, I can explain why we choose to call our sisters "women in prostitution". It means women who have been forced into prostitution, or women who have been cheated. If you say commercial sex worker, implicitly there is a choice that the woman wants of her own to be a commercial person selling her sex. "Women in prostitution" does not have this social connotation.

Dr. Venkatesvarelou : I just want to know if there is any NGO controlling prostitution? Because prostitution is controlling this epidemic.

Prof. Hema Devaraj : What is the role of NGOs in controlling prostitution? I am working at Madurai government Rajaji Hospital as a professor and doctor. We used to see them in my service, which is the sexually transmitted diseases ward. The magnitude of commercial sex workers in and around Madurai city has been pointed out, but concretely what are NGOs doing? What are their positions?

David Thiagarajan : Image in Madurai, Community Action Network (CAN) launched by K. Pradeep and South Indian Action Programme (SIAAP) launched by Shyamala Nataraj in Chennai were three of the first NGOs to concentrate their efforts on prostitution. I will speak about Image very briefly. We have an integrated approach so that we intervene not only with the ladies involved in prostitution but with their husbands, the rowdies (local mafia), the procurers, the pimps, the brokers, the middle men, the policemen, the money lenders, the clients and so on. Our philosophy is that if we try to change the women's behaviour without having the support of their surrounding environment, efforts will be meaningless. In Tamil Nadu, we can hardly speak about women's empowerment if we do not interact as well with the other persons liable to mitigate this empowerment. Ultimately, the objective is to generalize and banalize the use of condoms, which is interpersonal matter when it comes to the point. But basically, sexual negotiation is undoubtedly a social matter. I have to say that we are not fighting systematically against prostitution, even if whenever it is possible we try, with the help of other NGOs dealing with social welfare and development purposes (protestants, caritative organizations), to rescue some of them. The problem is that we have limited material capacities. We just try to make prostitution safer in terms of women's health and social justice.

Dr S. Subramaniam : You said that you are distributing condoms to the commercial sex workers. What type of negotiations are possible and thinkable between the clients and the CSWs ? How can the situation be improved? If you clarify these points, it will be useful for the participants of the workshop.

S. Usha : I am ready to give ideas. I have done so before other participants at other workshops. If it would really be useful as you suggest, I am ready. I am afraid we are just producing abstract ideas without debating under which conditions programmes can be implemented. Implementation is 90% of the work, ideas represents only 10%.

S. Surender : Mrs Usha, though you would have spoken on sensitive issues at many conferences, we have not attended them. We ask you just to share your experience. It will be useful to us. Is the use of condoms always opposed by clients or by the commercial sex workers? There may be some who may not like to use condoms. On the other hand, child abuse and sex bonded labour are sensitive points that the government has so far not been able to solve. One may imagine that the government would prefer to hide the facts, to get rid of an embarrassing problem. But now media, NGOs, social scientists speak openly. At least, from the workshop point of you, we can discuss these matters. You have stated in your paper that the clients refuse to use condoms. The women are put under various constraints and they are forced have sex without the use of condoms. Several years ago when I was a member of the Population Control Organization, there were also people who absolutely refused to use condoms. At that time the problems expressed by the voluntary workers were different. Even the couples refused to use condoms during the fecondity period. Psychological reasons, intimacy reasons, virility reasons, and so many other possible explanations. With the advent of AIDS, when the question of life and death is involved, still the people are refusing to employ them. It is another dimension. That is why I am interested to know what type of experiences you have had or what type of comprehension you faced in this area.

Dr S. Subramaniam : Many studies have come up with detailed analyses of the reasons for not using contraceptives. Especially regarding condoms, it has been reported in rural areas that whenever the health worker is a female, the man cannot go and ask for a condom. The village folk will also not send their wives. The couple feel rather to go to the shop. But then comes the problem of availability. Condoms are not for sale in villages, but are only available in cities. I wonder whether similar problems of availability are faced by the commercial sex workers.

Ramkumar : We are working with the commercial sex workers in a small brothel based-area in Pondicherry. We are counselling the sex workers in jail as well. Through our focus group discussions that we had in the prison itself, we came to know that their knowledge was very high. But as far as the condom is considered, it is not used with clients. One reason is the non-availability of condoms at the site. In rural areas, it is not available because if you buy everybody will know. Secondly, the clients are not interested. According to the clients from the STD clinic we have interviewed, the clients are not satisfied with the condom. There is a question of quality, but not only. For example, a fifty-six year old man told me that using a condom is like taking a bath while wearing a rain coat. The sex workers are paid more for accepting unprotected sex, with or without the consent of the aunty (i.e. woman in charge of the brothel). Now if we consider occasional sex workers who are family housewives, there is a much lower perception of risk. Condoms are hardly used. What I want to want to stress is that in the brothel-based areas - not only in Pondy but in Mumbai, Calcutta - permanent sex workers are more insistent on the use of condoms. They are more willing and more in position to do so because, being together, they are empowered. In jail, we had discussions about sex-exploitation with the ladies also. Many of the sex workers have undergone stress and strain because of rape, forced group sex with three to ten men. It happens mainly with the rowdies, as well as with some "official groups" whose government affiliations I prefer not to mention in the seminar. Women said that during these collective assaults men hardly use condoms: if one starts without, the others will imitate him.

G. Geetha : There are a lot of beliefs linked with the perception of sexuality and body fluids. During the intercourse some of the clients tear the tip of the condoms because they are convinced that the loss of semen outside the womb will weaken their body and generate disease.

Jaya Karuppayee : When women suggest the use of condoms, immediately the male clients will ask: are you carrying an STD? Are you an infected person with the disease? Is that why you want me to use protection? But the client argues: "I do not want to wear it, I will go to see the next one". If she does not want to lose her client, either the client pays more because he does not care (drunken mood, self-confidence in the "power" of his body), or the lady has no choice but to guarantee him that she is not at risk.

Usha Raghavan : The awareness of HIV/AIDS is existing but both clients and ladies have their own interpretation: it is a foreign disease and more precisely a white man's disease. They always search for visible signs, they elaborate strategies to refute the danger, that it cannot exist in their own community (caste), that it cannot happen within their family. That is the main reason why many clients refuse to use condoms. They haven't felt the need. They have not started seeing the death. More celebrities have come forward in some other countries and said without fear that they have been infected with HIV. Not yet in India. I have worked in various countries in Africa and in the United States as well. I remember an African president who came forward and declared that his son was infected with HIV/AIDS and later died. In India, voices have not yet been raised. How many celebrities will be in a position to claim their status? I am afraid that right now, none of them want to do so. It would be, however, therapeutic. The

public can hardly imagine that HIV has appeared so dramatically everywhere in India. In some places, whatever the people come to know, to hear or to see through IEC (information, education, communication) they prefer to ignore.

David Thiagarajan : We have been working in the AIDS awareness field for the past six years in Madurai city and suburbs. We have faced many problems and much criticism. Even other NGOs once gave false news about Image, that we were promoting prostitution and so on. Despite this, we continue to work sincerely. Distribution of condoms in Madurai city is, as I said earlier, one of our main goals. In Madurai, the prostitution is of a different type. But we have to say that still today, in most of the places, condom usage is deficient. In the cheap brothels which are near the bus stand and near the pick up points (place where clients are taken to brothels and/or lodges), the clients are given a limited time, only five minutes. Generally, there is an understanding between the manager and the sex worker. For maximum five minutes, there is no time to use a condom. The women will think that if a man uses a condom, he will take more time to ejaculate, and in the present case the man is paying for a shot with a very limited time. If the man stays more than five minutes, the lodge manager will come and knock on the door, urging the couple to get out. The man has to pay twice if he does not go out immediately. So using condoms in this kind of lodge is not possible. In brothel houses, we are giving awareness to the sex workers every month or twice a month because there is a turnover of girls. The new sex workers who are employed or coming from time to time in the brothels are more able to refuse to have sex with the clients who have taken alcohol. But then, some of the sex workers, within two months, are forced to drink or initiated to alcohol. Becoming drinkers themselves, they do not refuse to work for alcoholic clients. Worse, the sex workers who are inebriated, don't bother to use condoms. The girl will not be able to remember how many clients came and enjoyed her the day before. Drug addiction is also common: pills, tranquilizers, ganja but rarely heroin. There may be self-help groups of prostitutes, but it is not common in my area.

Edward Laurent : Unlike the men who, being aware of HIV/AIDS, will bring a new razor to the barber shop, and insist on using the razor owned by them, the same person will not use condoms. It is a side-effect of the target group prevention campaign: instead of contacting only the sex workers, awareness should as well concentrate on the general public. I will give an example. In the village, the so-called rich people own a razor set. Nobody else will touch that razor. Only he will use it, wash it and to keep it. Whereas the poor people in the shop have to share the same razor. It is the same thing with the use of condoms in the cheap brothel where low class people go. They use the same girl in quick, unhygienic and unprotected conditions. While rich people go to call girls who have a restricted clientele..

Dr S. Subramaniam : We have to analyse both sides, the clients and the sex workers. When the client becomes inebriated, he will then generally not use condoms at that time. Because once drunk, he forgets everything. And even if he wants, he would not be able to put on the condom himself. Are the sex workers willing to put the condom on the man if needed, or do they just wait for the man to do so?

David Thiagarajan : The situation has changed and they are not shy about putting condoms on men's penises. The newcomers and young ones may face difficulties in the beginning, but they learn quickly. There is no repulsion in this. Another problem with us, NGOs, is that we are forced to have targets and achievements. We have to select some targets, we have to show the corresponding achievements which sometimes are not the most important realizations according to us (the number of condoms given out in one month, for instance). Imagine that in order to achieve the targets imposed by the funding agencies you decide to focus on brothel sex workers. But what about the customers ? You do not know who are they, what are the social mechanisms that lead them to the brothel and so on. You simply ignore it. Because it is not on your agenda, in your guidelines, etc. You have to show some progress in your programmed action. If you realize in the course of time that you have chosen the wrong target group, you will be criticized if you deviate in the matter. But how to explain your conviction, the necessity for a change in your action? It is a great dilemma. The apex body which wants an intervention on a particular aspect and not another will suppress the budget and your project will come to an end. However, we are aware that is time to change: instead of concentrating on the commercial sex workers we should shift to men as well.

F. Bourdier : I know David Thiagarajan well after having worked along with him during the last two years. His scope of action in Madurai goes largely beyond the field of prostitution. He has been struggling for the rights of the dalit people during the last twenty years in villages by trying to organize them, sometimes at the risk of his life. He is very particular to integrate his approach to sex workers into a broader socio-economic context.

K. Santosh : Speaking about women in prostitution led the authorities, the NGOs to consider them as a "high-risk group". This concept has been extended to many other groups in India. It has some policy implications and resonance among the population which are not without danger. That is

why Usha strongly rejected the idea that sex workers are the vector of the disease. From a human point of view as well as from a scientific one, it has to be refuted.

F. Bourdier : Effectively, a problem has arisen in our discussion when speaking about a group at risk, or a vulnerable group. The expression "groups at risk" has an epidemiological background, but most social scientists have for long been pleading for the need to change this designation into another. Moreover, it has an ideological content in the sense that it supposes that a society is compartmentalized in heterogeneous groups, each one of them having a homogeneous pattern. But it is always controversial to consider a group as a whole. It gives a caricature of an imaginary, static, segmented society. I agree with those who argue that it is more adequate to use a more comprehensive concept like "situation or social configuration at risk" which is a more inclusive, dynamic and less discriminatory concept.

Dr Venkatesvaralou : We speak about sex workers and then automatically about condoms. The use of a nirodh⁴ is not 100% safe. I heard not only from many experts but from an infected person who said: "I used condoms but I got infected with HIV". Many people also do not know how to use condoms. A condom does not guarantee safe protection. Some persons may ask: "How many times do we have to take it? When? With whom?". There is no doubt about the risk of using a condom. We used them for the family planning programme but the failure rate was about 30 to 40%. It means that the sperm has entered via the so-called cover. As far as HIV is a virus, the possibility of entering through the cover is also there. The second problem is how to use a condom? How to wear a condom? How often must it be changed? The people working under me in the Pondicherry AIDS cell did not receive proper training. So how can they advise others? Thirdly, promoting the use of condoms induces improper ideas about sex. Adolescents may talk about sex and develop the desire to have intercourse because they have heard about condoms. People will be encouraged to go to brothels because of condom promotion. It will definitely affect the morality of the people. Recently there was a proposal by an NGO, which wanted to intervene with higher secondary school students. The first aim was to create awareness among them. The second objective was a programme of condom distribution. I rejected the proposal. It gave the wrong impression that HIV/AIDS can be controlled by the use of condoms. One should not talk about that to them.

John Dalton : (Standing, speaking in a defiant manner) : What do you speak about? *Your* morality or *my* morality? You are completely confusing prevention and chastity. It is not acceptable, either being Indian or non-Indian. I am terrified to hear such irresponsible statements from a director of an AIDS cell who represents the public and secular sector. Your duty is to provide awareness and not to select those who are liable to hear and those who are not allowed. You feel proud to have rejected the proposal under the pretext of a non-culturally acceptable promotion of sex. You should remember that if you deliberately decide not to inform me about a deadly danger, you *kill* me. Every Indian citizen, irrespective of age, has the right to receive proper and objective information on the epidemic. Hiding the facts is nothing but a crime.

F. Bourdier : Dr Venkatesvaralou have raised an important issue that automatically leads to controversy. To argue and to discuss are the reasons for the seminar to be held. People are here to react. I do agree with John Dalton that the government has to disseminate the message to the entire population. The young generation should not be the victim of our preconceived ideas. One cannot distinguish between who has the right to know and who does not have the right. You seem to have chosen your ethic of conviction against your ethic of responsibility. Try to think about this. Anyway, there are scientific social studies all over the world which have shown that making condoms available does not increase sexual activity. Please, do stop using the false correlation between condom knowledge and more sexual intercourse.

Dr V. Jeysingh : We did a survey in Bangalore among college students from the 10th standard 12th standard (pre-baccalaureat) and in college (pre-University) on sexual behaviour. We found that among the college students who had sex, 70% of them had their first experiences with the prostitutes. Out of the 70% of college students who had sex with the prostitutes, 40% did not use a condom. They did not use condoms, not because they did not know the danger, but because they were ashamed to buy it and to put it on. At the same time, they didn't know how to use a condom. Our institute conducted awareness programmes in schools on HIV/AIDS, but in the government schools we were stopped from exhibiting to students how to use a condom. There was no other option but to stop. Then we went to other schools. They wanted us to give a lecture on HIV/AIDS, but they did not want us to talk about condom usage. They did not want us to talk about it because a lot of parents came and complained by saying: "Do not teach that to my son (or daughter)". We again had to stop because parents objected to such an education. "Our children have to be educated; you have to guide them in a proper way". It means that we have to educate parents first?

⁴ A brand of condom which has become a generic term.

Dr P.K. Das : I would like to temper the conflict. In fact, there is no conflict at all, but participants are talking in different ways. Dr. Venkatesvaralou was the first to object to sex education in the name of morality. What he is trying to express is that new education will expose students to new ideas. Parents see what is happening in Western culture regarding HIV/AIDS. So they are afraid that if same messages go to their children's school, they will be affected. That is why the parents are objecting to this type of modern education. In that case we have to educate the parents before the school children. These are types of approach which are different, not in nature, but in hierarchy of order. I have been working with the NGOs since they emerged nearly twenty years back. Fortunately, I was very enthusiastic when they started. I was thinking that they would fill the gaps separating the researcher, the medical staff and the people in the community. But we are still waiting. We look at one side of the coin and go and try to impose it. I have realized that paradoxically NGOs are very directive and not flexible. It has earned them a very negative image and their impact is in some places ambivalent. We don't mind in educating the children, but in the right manner. What is wrong in trying to define what we mean by "right manner"? In the case of AIDS, if the parents object, first you have to educate the parents. Then you go to the students. Then you have better acceptance. We also have not to rely on external assistance. Everybody in his life should act with humanity, that is to say as a social worker.

F. Bourdier : The students in contemporary India have not waited for the prevention campaigns to be exposed to or influenced by the West. Television, modern movies, satellite cables, youth magazines, etc. are available everywhere, even in many rural areas. It is time for the adults and for the educators to take into account the contextual situation of pluriculturalism. The good old time is no more. I know that in India, the time perception is cyclic. It induces persons to believe that everything may come back...

Dr. Venkatesvaralou : Dr. Das said each person is an NGO because he himself is competent to talk on AIDS/HIV. HIV is not something that everybody can talk about knowing what it is. Actually, as Dr. Das pointed out, I have written to the Directorate of Education not to allow anybody to talk on HIV/AIDS in schools, unless they have been authentically trained. Only resource persons may be authorized. Because wrong news, incorrect informations is too often given. Free license given to NGOs to talk on HIV/AIDS may be dangerous. We have to check their knowledge before. What are the criteria? What are their qualifications? In my department, no medical officer can go on talking without knowing HIV/AIDS. Among the thousands of persons willing to create an NGO, I really wonder how many of them are competent to talk about HIV/AIDS? Are basic qualifications prescribed ? By the government or by any licensing authority ? Give me some clarification.

F. Bourdier : Three points should retain our attention. First, like in every lucrative occupation, one will find opportunistic persons trying to take advantage of the advance of the epidemic in order to make money out of it, to gain prestige or to earn other social advantages. I have encountered such groups of persons in Tamil Nadu and elsewhere. A lot of money is dispatched for HIV/AIDS and people are well aware of it. Second, you talk about the necessary qualifications of the NGOs. Government health administrators and private doctors have to be educated as well, not only NGOs. It is a general process which has to reach the leading segments of the society who are in charge of communicating, informing and educating the population about the epidemic. If the public administrators themselves come forward and try to subordinate the others, here starts the Daedalus problem of hierarchy and jealousy. Third, you mention about wrong information. We agree and recognize this as a matter of fact. But you should also add misinformation and the absence of sufficient information.

Impression of Implementation Project on HIV/AIDS in Maharashtra
Dr. Shukla, J.Y ., Dr. Mrs. A. Mhaskar - Chief Sociologist, Miss S.A. Kelkar - Social Worker, L.C. S. Sabnis - Chief Manager, Nashik
(Maharashtra)

Introduction

The Maharashtra T.B. Sanatorium is an old non-governmental organization working in the field of tuberculosis since 1934. It is located in Nashik in the State of Maharashtra, about 180 kilometres from the state capital Mumbai.

The sanatorium has been, since 1969, managed by the Nashik branch of the Indian Medical Association (IMA). It is situated on five acres of land (about two hectares) and has complete infrastructure to accommodate 120 patients, with all the facilities to treat and investigate the in-patients. Five consultant chest physicians, one resident doctor, as well as a chief sociologist (a doctorate in sociology), and two social workers attending to sociological and non-clinical aspects of the patients, are working in the sanatorium. For clinical work, sufficient paraclinical staff is available.

Beginning roughly in 1992, the consultant physicians started finding that a number of cases showed deterioration without responding to drugs, and that there was an increasing number of Mortality Death Rates (MDR) cases.

Subsequent to discussions among themselves, as well as with the management and members of the Nashik branch of the IMA, a mandatory HIV testing on all patients was considered. All the aspects of such testing were deliberated, including counselling and confidentiality. It was felt that the advantages of a mandatory HIV test outweighed other aspects.

Such mandatory testing was instituted in January 1995. Since then, we have detected 112 cases of HIV infection amongst TB patients up to May 1997. We started in June 1977 a project on AIDS in our institution. As the project on HIV/AIDS envisions a prospective study of such cases, it was decided to carry out a retrospective study of these 112 cases :

Total admissions from January 1995 to May 1997	2195
HIV-positive cases detected	112
Percentage of HIV-positive cases	5,1 %

This percentage of patients does not reflect the true picture. Some cases were referred with HIV-positive status. Unfortunately, such cases were not taken on record as HIV- positive, but treated in the sanatorium. As the number of such cases is very difficult to assess, the percentage of cases is lower than as reflected in these statistics.

The socological research

- The objectives of this retrospective study are defined as follows:
- a) to study the natural history of HIV-positive tuberculosis ;
 - b) to find out, if possible, the presence of HIV among family members ;
 - c) to study the socio-economic impact of HIV on the family members ;

d) to undertake at a later stage case studies of a few families.

The methodology used to carry out this study is as follows:

1. As a first stage, letters were dispatched to all the patients inquiring about their health. They were accompanied with reply-paid cards so as to get responses from the patients.
2. The next stage is to go to the residence of patients who have not replied, to find out their current status and difficulties. Visits are also being planned to those patients who have replied to our letters.

The objectives of home visits are:

- 1) to find out the reasons for failing to come for follow-up at the sanatorium ;
- 2) to obtain first-hand information about the socio-economic status and lifestyle of the patients ;
- 3) to provide some guidelines for the selection of families for case studies ;
- 4) to ascertain the exact cause of death as certified on the death certificate.

With these remarks, the present preliminary statistical data collected until 30/09/1997, are tabulated under:

Table 1 : Distribution of patients according to the geographical area :

S.NO	DISTRICT	NUMBER OF PATIENTS	PERCENTAGE
7			
1	Nashik	86	76,78
2	Ahamadnagar	15	13,39
3	Thane	05	04,46
4	Mumbai	04	03,57

5	Dhule	01	00,89
6	Pune	01	00,89
TOTAL		112	100%

Table 2. Taluk-wise distribution of Nashik District :

S.NO	AREA	NUMBER OF PATIENTS	% OUT OF 112 CASES
1	Nashik City	44	37,05
2	Niphad	12	10,71
3	Igatpuri	10	08,92
4	Sinnar	08	07,14
5	Dindori	03	02,67
6	Chandwad	02	01,78
7	Malegaon	02	01,78
8	Kalwan	02	01,78
9	Surgu na	02	01,78

10	Manmad	01	00,89
11	Bhagur	01	00,89
	Total	86	100%

Table 3 : Age-wise distribution

AGE	M	F	TOTAL	PERCENTAGE
15 to 20	00	01	01	00,89%
21 to 25	23	04	27	24,40%
26 to 30	31	01	32	28,57%
31 to 35	12	01	13	11,50%
36 to 40	12	05	17	15,17%
41 to 45	06	01	07	06,25%
46 to 50	06	03	09	08,03%
51 to 55	05	00	05	04,46%

56 to 60	01	00	01	00,89%
60 to over	00	00	00	00,00%
TOTAL	96	16	112	100%

Table 4 :Gender-wise distribution

	MALE PATIENTS	FEMALE PATIENTS
MALE	96	85,71%
FEMALE	16	14,29%
TOTAL	112	100%

Table 5 Type of Response to Letters

Death confirmed by relatives through letter	19
Answers received from the patients	10
Patients attended follow-up	03
Letters returned because of incomplete addresses/ resident having moved	08
Total	40

Table 6 : Percentage of deaths calculated from the letters responded to by relatives of patients.

Total response received	32 cases
Deaths	19 cases
Percentage of death	59.37 %

Based on the foregoing statistical data and on our impressions, the conclusions are as follows:

- a) Tuberculosis and HIV are a deadly combination. Death occurred within a period 3 to 6 months from the detection of this combination.
- b) Drug compliance is very poor in such patients. This is one of the causes of early death.
- c) Observed treatment is best for such patients. Ideally, they should be admitted to an institution like ours for a period of not less than three months, where drug compliance is best. Unfortunately, the finances of our patients and of the institution do not permit of the admission of such in-patient treatment free-of-charge.
- d) As far as counselling is concerned, we feel that the present concept of counselling with a stress on safe sex practices is not adequate in our milieu. The role of counselling should be institution specific. Here the situation is such that patients have hardly any sexual desire or contact. Under these circumstances, counselling on these lines is meaningless, and we prefer to stress drug compliance and better nutritional practices. This may give a better quality of life for a longer period of time.

We feel that there are no specific prescriptions or guidelines concerning counselling. It should be situation specific, relevant and rewarding both to the patients and to the counsellor. Several comments were made to us before starting the programme of writing letters for follow-up to HIV patients. First, we were said to be exposing ourselves to a breach of confidentiality by writing letters to HIV-positive individuals, and second, we were exposing ourselves to discrimination by writing letters and planning for residential follow-up of HIV-positive patients.

These remarks were made by persons of high standing in the field who are authorities on the subject. Hence we have termed them curious remarks. With these remarks in mind, we have decided to go ahead with our projected programme and face the situation as and when it arises.

We want to raise the following questions and request advice on these points from this gathering.

- 1) To what extent is confidentiality to be held?

2) Does the follow-up of one's patients constitutes discrimination?

These are only our preliminary observations and impressions. When the study is complete, we will be able to give a more detailed and complete report on these aspects.

The next important aspect of our project is the survey of local doctors. As we want to impart proper knowledge regarding various aspects of HIV/AIDS, we thought we should have information about the level of knowledge and the needs of local doctors. During the last few years, a number of seminars, symposia, workshops and lecture series have been held by several government organizations and NGOs. We think that we can assess the impact such seminars, etc. had on the doctors.

The methodology adopted to carry out the survey was a self-administered questionnaire. This questionnaire was prepared after discussion among all persons involved in conducting the survey. The chief sociologist conducted a few interviews with a trial questionnaire. After the pilot survey, the design of the questionnaire was considered. The survey started in mid-July 1997. A total period of four months was allotted to collect the data from the doctors, i.e. up to mid-November 1997.

The questionnaire has two parts. The first part was specifically designed by our chief sociologist for the study of the sociological profiles of our local doctors. It was thought that we can approach doctors only once and we could therefore obtain data on sociological aspects in the same questionnaire. The questionnaire was designed with the following objectives in mind:

1. to study the knowledge, attitude, behaviour and practices (KABP) of doctors in our area ;
2. to study the impact of previous educational efforts on the doctors ;
3. to study areas of knowledge for doctors which require emphasis in our educational programme ;
4. to study the sociological profiles of doctors in our area.

There are about 1100 doctors within the corporation limits of Nashik who are members of various associations. It is estimated that an equal number are not members of any association. It was decided to obtain the data from doctors practising any system of medicine, irrespective of qualifications. Keeping in view our scope and infrastructure, our target is to cover in this survey about 25 to 30 per cent of the doctors practising in the town.

While the survey is still going on, we have received 397 questionnaires from doctors as of 30 September 1997. We wanted to give a complete analysis of questions, but due to circumstances beyond our control, such as computer software failure, we cannot give a complete analysis. A few questions which have been analyzed are being presented as a preliminary study of the survey. With these remarks, I turn to the data collected by us.

Question 11

Have you come across in your practice any HIV- positive person?		
Yes	201	50.7
No	167	42.0%
No response	29	07.3%

Total	397	100%
If your answer is yes, what is the approximate number?		
1	46	22.9%
2 to 5	93	46.3%
more than 5	62	32.8%

Total	201	100%

The conclusions drawn from this are:

1. A majority of doctors have seen a case of HIV infection in their practice. Hence they are aware of the infection and they have some knowledge of it and of its clinical manifestations.
2. A surprisingly large proportion of doctors have seen more than 5 cases of HIV/AIDS in their practice. This data is in our view not concrete, and will only become available on completion of the study.

This does not give any idea of the prevalence of the disease in the society since one patient may have several doctors. The impression created is that the infection is spreading rapidly in the society.

Question 13

Is AIDS a notifiable disease? (like cholera, polio, etc.)?		
Yes	73	20.4%
No	285	79.6%

Total response	358	100%
If your answer is no, should it be made a notifiable disease?		
Yes	190	56.5%
No	146	43.52%

Total	336	100%

Question 14

While considering the issues involved in HIV infection, whose interest is paramount according to you?		
Society	268	72.4%
Individual	60	16.2%
Both	42	11.4%

Total	370	100%

The conclusions drawn from the responses to these two questions are:

1. Most of the doctors are aware that HIV is not a notifiable disease, but a majority of the doctors feel that it should be made such.
2. An overwhelming majority of the doctors feel that society has priority over individuals in connection with HIV/AIDS problems.

Taken together, these answers reflect that doctors give importance to society over the individual when considering the issues involved in the HIV/AIDS infection.

Question 18

Do you feel that AIDS testing will be an important factor in arranged marriages in future?		
Yes	120	56.6%
No	46	21.7%
Don't know	18	08.5%
Against our social customs	38	17.9%

Total	212	100%

The response to this question has been given by more than 50 per cent of the doctors participating in the survey. In fact, this question was included in the questionnaire as an afterthought. During our pilot survey to determine the final design of the questionnaire, some doctors told us that there were a few parents of prospective brides and grooms asking whether they should ask for an HIV test by the

groom or bride before marriage. To this question we have no answer. We therefore included the question to find out the views of the doctors on this point, for it is usual for many people to ask doctors health-related questions regarding the prospective bride or groom.

The statistical data is revealing. The majority of doctors responding to the question feel that it is going to be an important factor in arranged marriages in the future. Keeping in mind that today in India, most of the marriages are arranged, it is of great importance. We will have to consider it from the point of view of confidentiality and discrimination. In order to provide us with some guidance, I would request the audience to discuss this aspect thoroughly, namely: Should we ask for premarital HIV testing of prospective brides/grooms?

Question 25

Will you treat HIV-infected patients in your clinic or hospital?		
Yes	137	36.7%
No	236	63.3%

Total	373	100%

Question 26

Will you treat HIV-infected patients if proper facilities are provided by an institution?		
Yes	270	84.4%
No	50	15.6%

Total response	320	100%

The statistics tell us that:

- 1. A fair percentage of doctors in our area are willing to treat HIV/AIDS cases in their private clinics/hospitals.
- 2. A majority will treat such patients in an institution where all facilities for treatment are available.

The conclusions drawn from the above observations are:

1. The survey shows that a majority of doctors are willing to treat HIV/AIDS cases if they are given proper facilities/knowledge.
It brings out the fallacy expounded by various reports in the press that a majority of doctors would not treat HIV/AIDS cases.
2. Doctors, at least in our area, do not consider the HIV/AIDS infection as something which should be shunned.

This conclusion, considered along with the conclusion drawn from Question 11, gives probable reasons for the willingness of doctors to treat such cases. They consider it as a purely medical problem. They have accepted it as an evil which is going to stay with us and have, therefore, decided to contribute their efforts in the battle against this infection.

Question 27

Which organizations are working for the prevention and control of AIDS?			
1. National Level:-			
2. At State level:-			
No response	275	69,3%	
Doctors answering the question by giving some name	112	28,2%	
Answered don't know	1		
0	02,5%		
		-----	-----
Total		39	100%

Analysis of answers:

Only the top five organizations were represented in the responses.				
<u>At the national level</u>				
	percentage of total response		of 112	
1. WHO	17		15.2%	
2. NACO	15		13.3%	
3. National AIDS Research Institute		11		09.8%
4. SOS FOUNDATION	04		03.5%	
5. ROTARY CLUB	03		02.6%	
<u>At the state Level</u>				
1. Maharashtra government	20(27)		24.1%	
2. JANKALYAN Blood Bank	20		17.8%	
3. Maharashtra TB Sanatorium	09		08.0%	
4. Indian Medical Association		04		03.5%
5. NGOs	04		03.5%	

Conclusions drawn from above data are:

1. No one responded with "Don't know".
2. Hardly 30 per cent of the doctors have any idea of organizations working in the field of HIV/AIDS.
3. At the national level, NACO, which is the apex body to coordinate efforts to control HIV/AIDS, is known to 13.5 per cent of the doctors responding to the question, while it is known to less than 4 per cent of 397 respondents.
4. At the state level, 27 respondents say that the government is working in the field, which comes to 25 per cent of the total respondents answering the question.
5. The doctors have responded by naming organizations like ours as working at the state level while, in fact, we are working at the local level.
6. Sevadham Trust, an organization which is a nodal agency to coordinate the efforts in the field for the state of Maharashtra, is known to less than 4 per cent of the respondents.

The implications of these conclusions are:

- a) The various organizations working at state and central levels do not have good public relations.
- b) In spite of the fact that NACO is an organization sponsored by the central government and has all the means of publicity at its disposal, it is not utilizing these assets.

The reasons can be:

1. inefficiency at the organizational level;
2. lack of public relations and co-ordination with proper agencies involved in publicity.

The same reasons apply for state-level organizations working in the field.

These are preliminary observations on data from the survey. In the next few months we will be able to complete the survey and analysis of the complete data.

After these comments, I would like to turn to some other aspects related to HIV/AIDS and involved issues. Our physicians are studying the natural course of HIV with tuberculosis and its clinical presentation. They will be presenting papers in proper medical/ scientific fora from time to time. Here we will consider non-clinical issues.

In the following we will present our observations and opinions regarding the issue of confidentiality and HIV status.

1. The socio-economic strata from which our HIV- positive TB patients are drawn have no idea of confidentiality. The concept is alien to them. They come from fairly large close-knit joint families, where day-to-day living expenses and medical care are looked after by the family as a unit. Under the circumstances, it is almost impossible to preserve the confidentiality of the HIV status. The head of the family, who is making efforts and spending money, wants to know the kind of ailment from which his ward or relative is suffering. He needs to know this in order to plan his expenses and to make arrangements for financing the medical care of his family member.

Confidentiality as a higher philosophical concept is completely alien to Indian philosophy and culture. It is a typical Western concept in which the individual is given priority over the society. Indian philosophy and culture have for millennia given importance to society over the individual. My argument is that reference to Sanskrit and Buddhist scriptures shows the underlying principle that the group or society is more important than any individual.

Thinking about this concept at another level, it is a struggle for supremacy between the individual and society. When we take an approach based on Indian philosophy and culture, our view on this matter will be much different. Otherwise we would not have been advised that approaching HIV-infected patients by means of a letter or home-visit would be a breach of confidentiality, or that we should not tell anyone about the HIV status of the patient, not even those who are caring for him. NACO and other organizations participating in sixty-five city surveys, have for many years been hiding behind the notion of confidentiality and not disclosing their data.

In conclusion, we must find our own solutions to various aspects of the question of confidentiality so that an individual is protected, but society at large does not suffer. This subject should be discussed until a certain consensus is achieved.

We have reached certain views about counselling. In our experience, pre-test counselling is alien to our patients. They do not understand the importance and implications of pre-test counselling. After listening to the discussion during counselling, they will give the doctor blanket permission to go ahead and carry out any investigations he wants. Post-test counselling is something which they do understand, because this is something to which they are accustomed in all medical situations. We feel that pre-test counselling should be dispensed with and only post-test counselling followed.

Difficulties and constraints encountered

We would like to place before this gathering of intelligent and public-spirited persons some of the difficulties and constraints faced by us. We do this in an attempt to find solutions to these problems.

a) The apex body, NACO, which is coordinating the efforts in the field of HIV/AIDS, is inactive. We have not received a reply to a single letter sent to them. We have therefore stopped writing to them.

The publications of NACO are not available anywhere. We had to make photocopies by begging from people who had these publications, but it is a very costly proposition to acquire them in this way. The only government publication reaching the people was *Caric Calling*, publication of which stopped a few years ago. Thus, the only authentic source of data and information is no longer available.

In short, NACO is perceived by us as a very unenthusiastic and public-unfriendly apex body. This is not to criticize NACO, but to bring to its notice our perceptions.

b) We find that there is an acute need for a directory of organizations which are working in the field, for want of which we are unable to communicate and exchange views with other organizations. If some organization were to take up the work of compiling such a directory, it would be a great help to all of us.

c) As regards financial constraints, the sanatorium is self-financing. We do not ask for grants from any organizations towards the running of the sanatorium. We did once receive a grant from Government of Maharashtra for an AIDS project, for which we are greatly obliged. In fact, some of the work presented here was possible due to this grant.

We find that funds are needed for the acquisition of equipment, etc. for sophisticated investigations concerning HIV/AIDS. We have no knowledge about funding agencies providing such grants.

Another area where we find need of funds is in the treatment of tuberculosis patients with an extremely poor economic status. Most of them need admissions for continuous weeks and must spend about Rs. 4000 during this period. Because the sanatorium is self-funding, it cannot afford to admit them free-of-charge. They must therefore be turned away. Occasionally, some philanthropist pays for a patient, but we are not in a position to help most of them.

Lastly, we have one suggestion. The government of India has launched a revised Domiciliary Observed Treatment Scheme (DOTS) for the treatment of tuberculosis. It includes distribution of drugs for sputum-positive cases only. We suggest that the government should also include cases of tuberculosis with HIV infection for drug distribution under DOTS.

Discussion

F. Bourdier : Doctor Shukla you are a representative of the private sector. You have undertaken a study on HIV/AIDS epidemic perception among biomedical doctors. In your paper you are suggesting some communication problems faced by the national bodies in India, specifically in the case of NACO (National Aids control Organization), and centres like the one to which you belong. You have raised some ethical points which will be discussed in the next session, like the priority of society over individuals, for instance. Your contribution has the advantage of showing how research as a production of knowledge is important for self-reflection and self-evaluation. In fact, you are questioning the functioning of the structure and you are putting forward the discrepancies in it.

Dr S. Sivaraman : Regarding the last point Doctor Shukla mentioned, I have to add something. You are speaking about the launching of debates on the National Tuberculosis Control Programme. I think that there is a misconception in the minds that the revised National TB Control Programme does not provide services for the infected HIV/AIDS patients. This is wrong. The revised National TB Control Programme just classifies all cases under various categories. The first category is infected TB patients. The second category is the failure case and category three is a specific provision that concerns other problems. You can treat non-infected HIV patients and HIV patients as well. You can treat the later for longer period treatment as they fall into the first category, provided they are clinically serious cases. The problem is not there. Another misconception is more important. People tend to link TB with AIDS. The government is very careful about that. Take the manual of the TB National Control Programme. There is a whole chapter on HIV along with TB (as the main opportunistic disease). So I think that it clarifies the false relation people may infer. Another doubtful dimension of your presentation regards the question of confidentiality, I am not going into the ethical part of it, but only as concerns the relation between TB and HIV. I am a TB specialist myself. You said that you have written letters. Under the National TB Control Programme, you should have written letters not only to HIV *and* TB patients, but to any TB patients. Like this there would be no arbitrary discrimination. No inquiry should break the confidentiality, because there are strict government rules about confidentiality. You have to write a letter to all TB patients if you follow the government rules. Naturally, because you are from a NGO, you can pick and choose. That is OK. If you write to everybody nobody is going to be know whether someone is a TB or HIV patient. Another critical aspect of your statement is about care. The concept now is primary health care. Any special TB worker or AIDS worker goes to the house of the patient. Confidentiality will not be broken. I will tell you a little story from my own experience. I was invited to an officers' dinner. There was a lady whom I knew from my profession. She is a post-graduate lecturer in a post-graduate college. The host is an IAS (Indian Administrative Service) officer. He wanted to introduce me to her, and as he did so, I realized that I knew her already as a patient. He was surprised and asked how I had come to know her. She was anxious and frustrated, you can imagine. I told him that her husband was my classmate. These are the situations that we have to manage. A last question I want to ask you: The questionnaire about the organization in the field, did it consist of multiple choice questionw or of open-ended questions?

Dr Shukla : For your information, I distributed these questionnaires in our assembly. A few copies are still available. It took about three months of part time work to prepare this questionnaire. The main use was for our medical association, not for any AIDS project implementation. It was our sociologist who wanted to study the social structures of the medical practices. So part one is mainly for the local use. The sociologist wanted to include the aims of the research in a different part about AIDS. But we could not analyse all the source manuals before September. We analysed the socio-economic aspects regarding AIDS. It was open questions. The second point is that some doctors were at that time exposed to a refresher course in a workshop or a governmental programme. Our investigation was done after a pre-test inquiry. My social workers started the field inquiry after three weeks of work. It is rare to get this type of questionnaires from the doctors. They usually don't give such importance to questionnaires. Another precaution that you say you hope that I would have taken is related to confidentiality. We made the questionnaire in two parts. We remove the name to keep the confidentiality. How do we manage to keep the confidentiality? We have to make sense of the study because if you don't write the name, the social worker will not come again and again to see you. So we gave duplicate numbers. I consider what you are saying. You are welcome if you don't write the names. But I am a senior doctor. I have a schedule for the doctors to get the information. Otherwise it is impossible to collect the merit questions. Among those interviewee, only two persons told me that they did not want to write their names. Nobody else objected to disclosing their names. Some people asked me "Why doctor are you not writing our address and other things?". Afterwards, we made the survey available to everybody who wanted to participate in it. On the basis of this questionnaire, dissemination methodology is as important as dissemination of results.

Prof. Gurumurthy : I want Doctor Shukla to clarify a few questions. Since you are in touch both with HIV and TB patients, I would like to know if you have any break-up for the cases who have got both? TB patients have HIV and HIV patients have TB. The second point is the background of the positive cases. You just mentioned HIV and TB cases. Sex background you have given. But what about the socio-cultural and economic components? Since this morning we have been talking about prostitution and social aspects of the epidemic, such parameters are needed because once a person becomes a TB patient, then marriage prospects and employment opportunities are less. In such cases, some women may become prostitutes. That is what I am trying to connect these points. The second objection is related to the use of the terminology "Have you ever seen an HIV-positive case?". It is a different word from examining, providing care and treating. Medical terms are different. You have to be careful about that because it may lead to misunderstandings. My third question is about the assessment where you ask the pathologists if there are sufficient laboratory facilities for the doctor to make special diagnoses? For HIV, he needs special equipment. The

ones you interview are general practitioners and you are not giving any information about it. Last but not least, we do not know if all the 1100 doctors are from Nashik town, and you have not given the break-up according to category of physician, like biomedical doctor (MBBS), homeopathy practitioner, Registered Medical Practitioner (RMP), etc.

Dr Bobby Zachariah : We run a hospital in Jawadhar hills for TB patients and in our building we have in-patients facility for up to 25 persons. It is always full. 80% of the out-patients attempt to obtain hospital treatment. Secondly, about drugs for immunization for TB. We found that if the patient is using the drugs supplied by the TB sanatorium, the improvement is not as good as it is for drugs available in the open market. It is wrong to believe that the government supplies drugs in substantial quality. That is why we have to buy the drugs from the open private markets. The price is high in the open market but at least it is available. It costs about 60 rupees per dose (only for TB cure). Out-patients coming to our hospital cannot afford it. Thirdly, we found that because of the stigma attached to TB, they are not willing to buy the medication by themselves. A lot of families prefer to go to buy the drugs in non-identified places rather than maintaining the patient out of the house. Families prefer to provide them medication at home. I am talking about the lower strata of the society. In addition, a lot of people who are HIV positive are given TB medication. Some of them have allergies. These are new reasons which make them stop the medication for TB. In other words, TB patients who are HIV positive are in many respects more socially vulnerable and liable to remain uncured.

Dr Gurumurthy : Is it advisable to continue a costly co-therapy on HIV patients in that case?

Dr S. Sivaraman : I object to the declaration made by Bobby Zachariah. He said that the government is providing substandard drugs. I am a TB control officer. I am providing substantial drugs. Do you have any facts and figures that could say that governmental drugs are not effective while the drugs available in the free market are more effective in terms of quality standard? Such a statement should not be raised without facts and figures in a scientific forum like this one. TB drugs are supplied by the government of India. We have clear-cut rules, procedures and standards, and quality control is made at various levels. An independent research institution is controlling the quality and is testing the drugs before supplying them. It is at present watched over by the World Bank under the Revised Control Programme. So, please, don't make disruptive remarks without supporting them by facts and figures. If you do have figures, please produce them.

F. Bourdier : I think Bobby Zachariah was speaking about the perception of the people, which is something different. The government may be providing quality drugs or not, that is the not the question. In any case, people have their own social representations. They get the impression that drugs are of low quality because they are free, because the colour of the pills is white, and for any other complex reasons. I remember eight years ago I was studying health behaviour in three villages near Coimbatore. In one village, there was a Primary Health Care centre and the rumour was going around that all the drugs provided were inefficient, because they were small and had the same colour. Of course, as a social scientist, you cannot take this point as matter of fact. But it is people's perception and it definitely has a meaning. Not that the drug in itself was bad, but something in the public service was not right. In that case, it was the social relation with the medical staff. In other words, what the people maintain is of importance: whatever it is, we have to find out the hidden structures behind it.

Dr Bobby Zachariah : It is also there. But when you are talking specifically about TB patients and medication it implies availability of four drugs. It is difficult for patients when they go to a TB sanatorium to get all the four drugs simultaneously. TB Sanatoria will have only two or maybe three of the drugs. They will not have all of them. Patients have to go to other places to get the remaining one(s).

Dr S. Sivaram : The government has a network of primary health centres. These primary health care institutions provide free drugs. Sanatoria are concerned only with in-patient treatments. I have been chief of a TB sanatorium and am now chief of a district TB sanatorium. So I have experience in both. After having been discharged by the sanatorium, the patients take care of themselves. Any patient who has not been admitted and who is going for domicile therapy has to approach the nearest primary health centre and has to ask the district tuberculosis centre for drugs. There is an index which is maintained at the district level and they will be given drugs if they are included. There may be some indifference because of logistical problems, I don't deny that. But everybody is getting drugs. Most of the time, because of the revised National Tuberculosis Control Programme, dearth of drugs is not common. It used to happen, I do agree. Because there is logistical support, there will be logistical problems. There is one cell in Delhi. When I asked the question "Why, sir, are you not supplying drugs?", he replied

"Come and see me. You will see my staff. I have 412 districts in India to look after but I have a staff of five people including one personal assistant, one clerk and one store keeper. That is all I have". This sort of logistical problem is there. Whom do we have to accuse?

Dr Shukla : One of your questions was whether the case be HIV or TB. Now that we are giving interest to research study, we do need information. But, regarding HIV and TB, is difficult to find out who is what. There is a separate questionnaire which we have prepared. We have not distributed it to everybody. We will give it only to those who are really interested in prospective studies. If it is relevant, from that prospective study we can find out what comes first: whether TB or HIV. Regarding what Professor Gurumurthy said when asking doctors about their confrontation with an HIV patient, it does not mean that the doctor had ever examined a patient. It does not mean that a doctor had seen HIV or TB coming first. But it means that a doctor, in particular cases, may be in position to assess the clinical evolution of his patients.

Male respondent : My point is whether a clinical test is needed to determine whether a person has HIV or not.

Dr Shukla : I am coming to that. There is a misconception that the HIV test is something very difficult to undergo. Nowadays, if you take an HIV test with the modern technique which is available, you will realize that there is no point of being anxious. With modern techniques, it costs less than 80 rupees and even a small boy can do it. It does not require beds or other costly facilities. It does not need much of technique, a reliable test can be done in the laboratory of the clinic. So do away with the concept that this is very difficult task. It does not require any particular knowledge or equipment. You simply buy a kit and everything is available in it. Coming to the advanced stage of our research: it is still going on and I did not give you a final result. One of our concerns is to know why doctors are reluctant to deal with HIV patients and what should be done to improve this situation. Treating a patient is natural and a must. But doctors are also human beings. They have personal fears about getting infected through injections, needles, etc. These small facilities are available in all the clinics. It is one of the reasons why the doctors are not willing to treat HIV-infected persons. Some of them cannot treat the patient and simultaneously change their materials. But another idea which generated a lot of discussion with a number of government and private doctors was about the general view that doctors within the next five years will have to treat HIV-positive patients irrespective of their initial decision. Simply because, if five to seven per cent of the population in India is HIV positive, than fifty per cent of the doctors will treat HIV-positive patients. It is a mathematical prediction that replaces the problem in an objective way.

F. Bourdier : From the research point of view, you have raised two issues which will be discussed in the two following sessions. The first one is about the medical and legal aspects of the epidemic. The second will be challenged, I hope, during the session dedicated to the role of NGOs regarding medication, and their ambivalent relations with government and international agencies.

Part Three :

Role of NGOs with regard to

medical research,

epidemiological, ethical,

socio and medico-legal

aspects of HIV/AIDS

Time trend of HIV infection in Pondicherry : Relevance of sociological research inputs
Dr.V. Sivaraman, Director TB Hospital, Pondicherry

Introduction

Since the first case of human immunodeficiency virus (HIV) infection was documented in India, there has been an increase in transmission and efforts to detect and contain it were put in operation at the national level.

The National AIDS Control Programme was implemented in the Union Territory of Pondicherry in June 1986 when blood samples of high-risk groups were collected and sent to the Christian Medical College Vellore to test for the presence of HIV infection. Subsequently, HIV testing facilities were introduced at JIPMER, Pondicherry. Since October 1992, the Rapid test for HIV infection has been carried out at the General Hospital Pondicherry for blood safety purposes. Full- fledged ELISA testing facilities at State AIDS surveillance were implemented in October 1994.

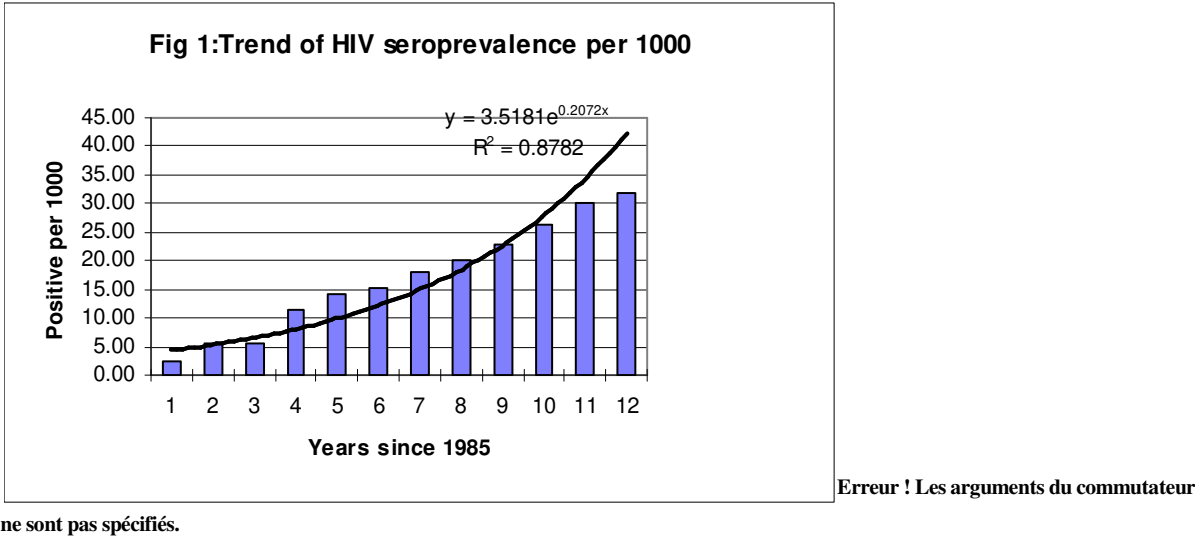
All the results have been analyzed and this analysis forms the basis of the present paper.

The aims of this presentation are:

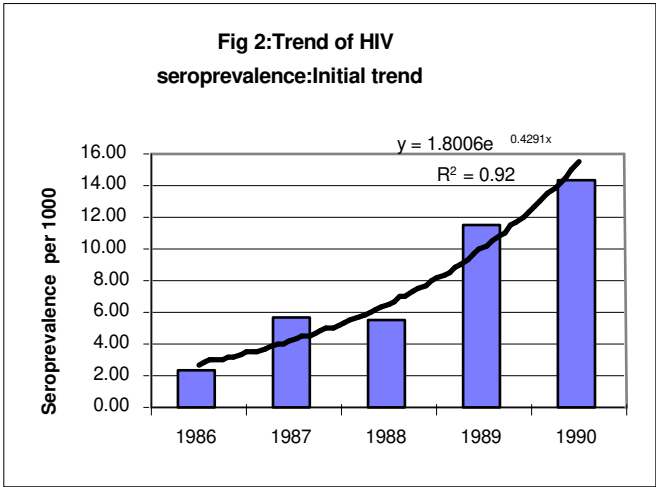
- 1.To study the epidemiological time trend of the HIV infection in Pondicherry
- 2.To attempt to interpret the observed trend, compared to the estimated trend
- 3.To examine the relevance of sociological research inputs for epidemiological studies and for planning intervention strategies.

The observed and estimated trends

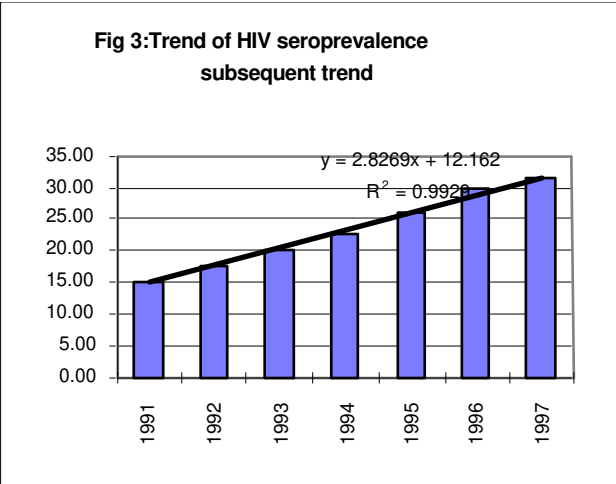
The cumulative prevalence of the HIV positivity rate among high-risk groups was plotted over the years. Anderson and May (1991) have developed a mathematical model and deduced that the positivity rate increases exponentially in the initial phase. Assuming exponential growth and using computer software, an exponential curve was fitted to the observed data. It is seen that the observed rates are very close to the estimated trends for the first few years.



The hypothesis that the epidemic follows an exponential course in the initial phase and latter becomes linear was examined. We had to determine from our data when exactly the growth curve of the epidemic curve became linear. This was done by using computer software envisaging a number of scenarios. It was found that the transition from exponential to linear growth must have taken place around the year 1990. (Vide Fig 2 and 3)



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Erreur ! Les arguments du commutateur ne sont pas spécifiés.

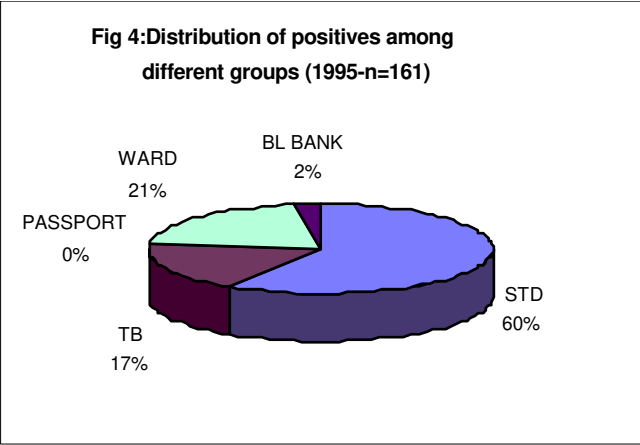
The reasons for the slower growth of epidemic in later years are not clear but could be all or any of the following:

- 1.The control measures being taken have had an impact and more and more people are adopting safer sex practices
- 2.The most susceptible in the sexually highly active categories are infected in the early stages of the epidemic producing saturation effects in these categories which decrease the exponential rise in incidence within them; although the incidence of infection continues to rise among individuals in less sexually active categories, the overall rate of increase is slower than exponential.

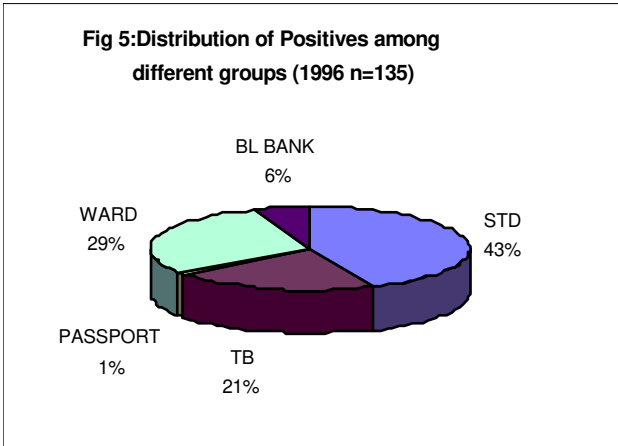
There are conflicting reports about the spread of HIV among the sexually less active population. While Bollinger et al (1995) maintain that there is evidence of a recent spread of the epidemic from high-risk groups to other risk groups in India , Pais((1996) feels that the penetration into the general population is uncertain.

The distribution of HIV positives among different segments of the population who have been tested for HIV has been analyzed to provide an insight into the existing scenario in Pondicherry.

(Fig 4 and Fig 5). The background information on total tested and HIV positive is shown in Table 1).



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Table 1: Background information on number tested and number positive

	STD		TB		Ward		Passport		Bl bank	
Years	95	96	95	96	95	96	95	96	95	96
Positive	95	59	28	28	34	39	0	1	4	8
Tested	1393	857	716	733	1031	1110	202	305	1972	1660

It will be noticed that the patients attending the sexually transmitted disease clinic account for 43 to 60% of cases and that the proportion of females is higher than males among HIV positives. They may form an important target group for counselling. (Table 2)

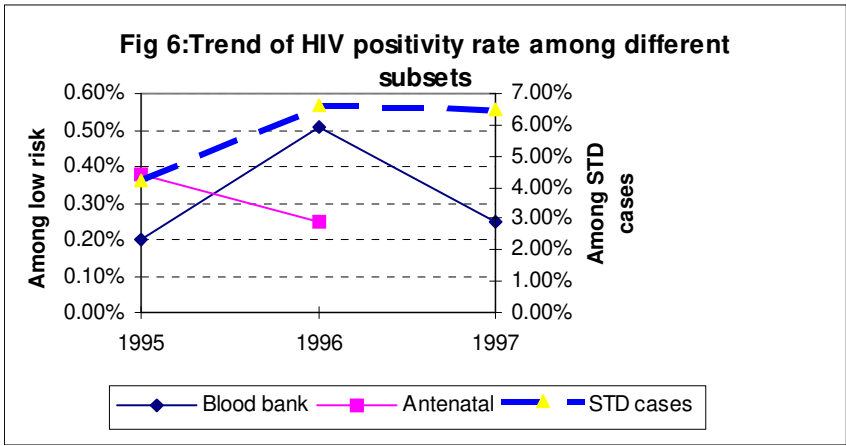
Table 2 : Sex distribution of STD cases and HIV status

	Positive	Negative	Total
Males	36	834	870
Females	30	310	340

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(P value = 0.001255 Highly significant)

The time trend of three well-defined subsets of population (antenatal, blood donors and STD patients) who have undergone HIV testing has been plotted (Fig 6). It is observed that there is no uniform increase in the positivity rate in the different groups.



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commutateur ne sont pas spécifiés.

In 1995, 4.2% of STD patients were HIV positive; This increased to 6.6% in 1996 but fell to 6.48% in 1997. (The figures for 1997 are provisional and the differences are not statistically significant p value=0.95 and 0.55: vide Appendix table). Therefore the hypothesis that the sexually active group is nearing saturation might prove correct.

Practical implications for planning intervention strategies.

Mathematically stated, the objective of any disease control programme is to minimize the number of new infections and disease. The potential for the spreading of a disease depends on the magnitude of the reproductive rate of the infection. This rate denoted as R_0 defines the number of secondary cases of infection generated by one primary case in the population where almost everyone is susceptible to infection-as in the early phases of the epidemic. Anderson and May (loc cit) have deduced that for HIV transmission

$$R_0=bcD$$

Where

- b=Average probability that an infected person will infect a partner over the duration of partnership.
- c=Average rate at which new partners are acquired
- d=Average duration of infectiousness

It therefore follows that for proper understanding of the epidemic, the determination of the above variables in a given country with its sociocultural background is essential; *here is a field where close collaboration between medical men and social scientists is imperative* if accurate epidemiological forecasts are to be made.

A closer look at the above variables and how these need to be manipulated if epidemic control is to be achieved. seem to be called for:

Average probability that an infected person will infect a partner over the duration of partnership: This would naturally depend upon the adoption of safe sex practices by them, presence of genital ulcers, frequency of sexual intercourse. Post-test counselling should be aimed at underlining these points.

*Average rate at which new partners are acquired :*The need to avoid multipartner sex should be emphasized.

Average duration of infectiousness: The early diagnosis and post-test counselling are aimed at minimizing this variable. This can conveniently be considered under four subheadings:

The incubation period

Time between onset of symptoms and seeking medical relief

Time between seeking medical relief and correct diagnosis

Time between correct diagnosis and adoption of safe sex practices

Sociological issues

From the foregoing it is evident that many sociological issues need to be addressed

- What is the average time which elapses between onset of symptoms and seeking medical relief?
- What is the source of ___?___ (govt or private) commonly approached?
- What is the difference, if any, in the efficacy of these sources in diagnosing, counselling?
- What proportion of patients change their behavior as a consequence of counselling?
- What counselling tools are most effective?
- Can any particular sociocultural profile of persons not changing their behaviour be delineated?

A lot would depend on how many of the above issues can be successfully identified and resolved.

As has been pointed out by Maticka et al (1997), "[s]uccess in the area of prevention will require a better understanding of the sociocultural and interpersonal fabric within which the transmission of HIV is occurring and prevention campaigns must be directed to more specific contexts and patterns of risk going beyond the 'use of condoms with prostitutes message'."

Appendix Table

HIV Prevalence among STD Patients

Year	HIV+	HIV-	Total
1995	95	1298	1393
1996	59	798	857
1997	47	716	763

Calculation of statistical significance of difference between 1995 and 96

Between 1995 and 96

$\chi^2 < 0.01$ DoF=1 Pvalue=0.952959

Between 96 and 97

$\chi^2 = 0.35$ DoF=1 Pvalue=0.556072

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Clinical Trial and Homoeopathic Medicine in the HIV infection

Dr Bhuvaneswari, Homeopatician, Government Hospital, Chennai (Tamil Nadu)

Introduction

The acquired immune deficiency syndrome, or AIDS, was first reported in 1981, in the United States of America. Since then, the causative organism, HIV, has spread to almost all parts of the world. The disease pattern presented by HIV is referred to as the HIV disease spectrum, of which AIDS is the final and fatal stage. AIDS is characterized by severe immunodeficiency resulting in the invasion of the body by opportunistic infections, such as pneumocystosis, and by the presence of tumours, such as Kaposi sarcoma and non-Hodgkins lymphoma. The interval between the acute infectious stage of the disease and the development of AIDS spans a period which varies from two months to more than ten years. The various stages of the HIV infection are classified on the basis of the immunocompetence of the patient, which is recognized by signs and symptoms directly related to the degree of immunodeficiency, and by laboratory parameters.

Efforts are being made to find an effective drug to combat the spread of HIV. It is only recently that alternative systems of medicine were called upon to help fight against HIV. Homoeopathic medicines have been used for the past two hundred years. They have been traditionally recognized to act effectively against various viral diseases, such as measles, influenza, herpes simplex, chicken pox, warts, etc. There is evidence to show that homoeopathic medicines are effective against viral diseases. However, this is the first time that homoeopathic medicine is being tried in the case of HIV.

Towards the end of 1991, the Central Council for Research in Homoeopathy, of the Ministry of Health and Family Welfare, Government of India, undertook the study (trial) of homoeopathic medicine in the treatment of HIV. The project was approved by the Government of Tamilnadu and research was started in 1991 at the Institute of STD, under the supervision of Dr. K. Jayapaul, Director and Professor, Institute of STD, Govt. General Hospital, Chennai, and the Medical College, Chennai. The drug trial has been in progress for the past six years.

Materials and Methods

The subjects of the study were patients attending the STD clinic of the Institute of STD, Govt. General Hospital, Chennai. Some patients were referred from the Sri Ramachandra Medical College, Chennai, and other cases were sent by various NGOs. The patients who tested positive for the HIV antibody in the ELISA test, or in a few cases, in the Western Blot, were recruited for the study.

Symptomatic and asymptomatic patients in various stages of the HIV infection were registered at the CRU, Homoeopathy. There were repeat tests by immunocomb method, VDRL test and routine laboratory tests for all patients. Based on the totality of symptoms and constitutions of the patients, the cases were individualized and treatment was started by computerized repertorization. Patients were told to come for a regular follow-up. The follow-ups of these patients were regularly monitored.

Services provided

1. Clinical services with regular follow-up ;
2. Investigations - haemogram, VDRL test, ELISA test for HIV ;
3. Referral of cases to various departments for systemic examination, diagnosis and investigation ;
4. Health education ;
5. Counselling services ;
6. Rehabilitation - social rehabilitation of CSWs and needy women through the agency of NGOs to encourage such persons to participate in income-generating programmes.

Observations and discussion

In this drug trial, a total of 318 patients were recruited up to September 1997. Of these, 143 were males, 169 females and 6 were eunuchs. Of the 144 under observation, 72 were males, 68 females and 4 were eunuchs (transsexuals). The total number of regular follow-up cases until September 1997 was 94 (43 males, 49 females, 2 eunuchs).

The following drugs were used in the treatment : lycopodium, sepia, phosphorous, sulphur, lachesis, which showed promise. During attacks, acidphos, belladonna, bryonia, rhustox, challidonium, chininum sulphur, nux vomica, phytolacca, veratrum album, were used. Feramet and vanedium were added to improve the haemoglobin status.

The role of homoeopathic medicine in improving the quality of life and inhibiting or delaying the progression of the infection was evaluated.

Conclusion

The role of homoeopathic therapy in the management of the HIV infection has been discussed and observations made during the study to indicate that homoeopathic medicine may be used as immuno-modulating agents which by delaying the progression of the infection prolong survival and improve the quality of life, without causing undesirable adverse reactions, i.e. opportunistic infections in HIV-infected individuals.

Acknowledgements

Our sincere thanks to Dr D.P. Rastogi, Director of the Central Council for Research in Homoeopathy, and to our supervisor Dr K. Jayapaul, Director and Professor, Institute of Venereology, Government General Hospital, Chennai, as well as to Dr Bhanumurthy RO, CRU, Dr P Prasad ARO, and Dr S.D. Fernandez, Assistant Professor of Venereology.

Discussion

Frédéric Bourdier : Research is being conducted at the national level and at the state level. What is the position of the government regarding classical medicine and AIDS ?

K. Santosh : Ayurvedic, Unani and Siddha medicine are receiving financial incentives for trials. Different national institutions are undertaking research in various directions : treatment for opportunistic diseases, delaying the decrease of CD4 cells and so on. Naturally, funds devoted to alternative medicines are minimal in comparison with money allotted to biomedical research. There is a lot of competition and conflict between the representatives of the different systems of medicine. In Tamil Nadu, the Siddha medicine is encouraged to test scientifically drugs which would be liable to reinforce the immune system. You may easily imagine that it leads to interpersonal and institutional controversies.

Dr Bhuvaneshwari : I am from Central Council for Research in Homeopathy (CCRH). We are the organization given the difficult job of finding a drug to cure AIDS. Actually, on a homeopathic basis, we started our research work in 1991 at the General Hospital, Chennai in collaboration with the STD Department, and so far we have got more than 300 cases. We have more than 144 cases to follow and we get good results out of this treatment, also with symptomatic patients. We have also suggested bringing viral load **technological** aparitus from New Delhi in our head office. They are soon going to establish a protocol, after that we have to elaborate the results of the homeopathic medicines and the efficacy of homeopathy in the treatment of AIDS. We do other elaborate investigations in our department, in the in-patient departments. We use our STD clinics and we are admitting the cases there. We are taking care of many CSW, housewives, destitute women. Nowadays, we are getting AIDS infected families. So many widows, children are on the list of the cases. Some voluntary organizations like Crecent, Zonota, are taking care of my patients. As I said, we do have some hope regarding the treatment. It is a scientific therapy, even if some doctors have problems understanding homeopathy. There are many similarities between curing the HIV virus (as well as infections) and the policy and philosophy behind homeopathy. We can do better than other therapies. We can serve the moderate standardized form of indigenous medicines and traditional medicines. If you go for electropathy which - you might have heard - is one type of electrochemical stimulant, on the same basis, homeopaticians can find a single similar drug. There is hope for the future.

F. Bourdier : I would like to know if this kind of research going on in Chennai will influence our colleagues in Bombay or at JIPMER in Pondichery?

Dr. D.P. Rastogi : Similar encouraging results have been undertaken at the Regional Research Institute for Homeopathy in Mumbai. A double blind controlled clinical trial of homeopathic medicines in HIV infection was conducted. The aim of the study was to evaluate the immuno-modulator role of homeopathic remedies in HIV infection. A randomised double blind clinical trial was conducted to compare the effect of homeopathic remedies with placebo on CD4^{ve} lymphocytes in HIV-infected individuals, conforming to CDC stages II & III, between June 1995 and February 1997. A protocol was drawn up which was approved by the Indian Council of Medical Research. One hundred HIV-positive individuals between 18 and 50 years (71% males) were included in the study. Fifty cases conformed to CDC stage II- Asymptomatic HIV infection, and the other 50 cases to CDC stage III. Cases were stratified according to their clinical status and CD4 positive lymphocyte counts. A single individualized homeopathic remedy was prescribed in each case and was followed up at a periodic interval of fifteen days to one month. A six-month study was performed for each registered case with evaluation of CD4 positive lymphocyte counts at three-month intervals; results were compared with the baseline immune status. In the scheme of PGL, a statistically significant difference was observed in CD4 positive lymphocyte counts between pre- and post-trial in the treatment group ($p < 0.05$) and the control group ($p = 0.75$). In the asymptomatic HIV infection, differences in absolute CD4 positive lymphocyte counts between pre- and post-trial levels were not significant. The study suggests a promising role for homeopathic treatment of the HIV infection, especially in the symptomatic phase as evidenced by a statistically significant elevation of the baseline immune status in persistent generalized lymphadenopathy.

Usha Raghavan: One question to Dr. Bhuvaneshwari: when have did you start giving the medicine? Are you informing the patients beforehand that they are going to be given your medicines and are they accepting ?

Dr. Bhuvaneshwari : We began more than one year ago. Naturally, we are counselling the patients and only then giving the treatment.

Ethno-epidemiology of AIDS and responses of Tamil medical science

Frédéric Bourdier, ANRS project, Bordeaux (France)

I was taken to listen to the discourse of representatives of the classic medicine Siddha (*siddha vaidyar*) concerning the causes of seropositivity and the means of curing it. For them, AIDS is a disease which has always existed, known under a different name, and it is possible to treat it on the condition that the afflicted person has not yet reached the final stage. The government legitimized traditional practices after Independence, and there are now schools of medicine at which one can acquire knowledge of Siddha, along with modern physiological notions. This type of Siddha, a sort of two-headed Janus, is not accepted by those who call themselves the pure upholders of ancestral knowledge. The latter, for the most part, denigrate the new Siddha medicines distributed by pharmaceutical companies and delivered in the form of pills, syrups and injections. The true practitioners of Siddha know to prepare themselves the remedies whose secret they possess. It is these claimants of an authentic medicine who declare not only that they are able to control the evolution of seropositivity, but that they can bring about a return to a seronegativity.

The time would have come for these practitioners of Siddha to assert new therapeutic abilities in order to promote a social recognition which continues to diminish. Faced with the fascination exercised by the rapidity and efficacy of biomedicine, their practice is in effect losing on momentum. Few people take recourse to them and, conversely, the new generation of siddha physicians is not replacing the older. The initiation is too long and difficult. Those who are ill rarely choose classical medicine which is seen more and more as an alternative therapy, gentle and without side effects, specialized in chronic ailments and serious diseases such as leukemia, arthritis, cancer and, now, AIDS. Since the appearance of the HIV epidemic in India, the practitioners joined in associations in various parts of Tamil country took counsel together to discuss the so-called new existence of the disease. It was identified as already being very old. The issue, which is easily understood, was one of size. Following a colloquium in 1994 on the theme "the AIDS epidemic and the role of Siddha", a charter was elaborated attesting to the power of the *Siddha Vaidyar*-s to recognize, control and vanquish the disease without difficulty. The assertion has its roots in the eighteen *Cittar*-s (Sivaite sages) who are at the origin of Tamil medical thought in which there exist a finite number of diseases (4848). The writers of the medical treatises - among which is the famous compendium by Thirumullar - have established from the beginning of the Christian era precise nosographies enabling of a categorization of different pathologies. The fundamental idea is that there is no intractable and no new pathology. Man bears in himself all, including the power to heal himself of all diseases and to free himself from death. One of the essential aspects is the concept of individual and social prophylaxis, intended to promote and defend a corporeal and psychological immunity. With the "resurgence" of AIDS, a discourse is evidenced which takes up numerous themes gravitating around the notion of moral prevention. The increase in the number of persons affected by the virus (*kirmuli*) which develops what is now called AIDS, formerly denoted as *pal uravu* ("touching", "kissing on the mouth") and *udal uravu* ("physical contact between two persons"), is the reflection of a malaise in civilization. Morals are becoming lax, ways of life decadent. Tobacco, drink, industrial pollution, insalubrity of hygiene, unnatural environment, promiscuity, deterioration of

diets, sexual immorality, shattered family life, rupture of ties of solidarity, depravity, absence of spirituality, neglect of ancestors and of the sacred, medicinal and other drug abuse - such are the parameters which contribute to the propagation of the epidemic. All that does not conform to a general ethics of behaviour is held to weaken the individual. He who has too many sexual relations demands of his body additional work to produce sperm, whence an immunity weakening which opens the door to all sorts of viruses. Just as he whose acts do not conform to traditional values leaves an opening for numerous diseases, including AIDS. Evincing are also the notions of wrong committed in a previous life and of bad constellations in the horoscope. There is not a single cause of the appearance of HIV, but several. The biological and the social orders harmonize, but it is not excluded that one conceive of AIDS as an extension, a deterioration of other diseases such as cancer, tuberculosis and the majority of opportunistic diseases which are found among those afflicted with AIDS. Medical anachronism, one will say. But, in the conception of Siddha doctors, there ultimately exists but a single disease, in the same way as there is a single God beneath the appearance of a pantheon of deities in Hinduism. These aetiological representations may be those of medical doctors, but they are not uniformly distributed in society. Until present, there has been a certain airtightness between the interpretations of the population, largely induced by the media and prevention campaigns of the government, and the assertion of the *siddha vaidyar*, who is orthodox, a scholar, an alchemist on the quest for a universal panacea. Nevertheless, by proclaiming oneself as a specialist of a mortal disease, the would-be offers to effect cures which he proposes do not remain without echo. Some publicize themselves in newspapers, or posters or on the radio. The recent intensification of the infection which they attribute to the decadence of moral values and the precariousness of living conditions is spreading in the population, it also being a fact that, contrary to MBBS doctors, these practitioners take time to speak and listen to others.

One is, therefore, justified in considering the implications of their position. Totally opposed to the prevention campaigns of the government and NGOs, what will be the result of this collision? Caught between two discourses, the people remain dubitative until the day when, affected by seropositivity, they are ready to accept anything offering a perspective of hope. A doctor from Kerala (south-west India), established in Cochin, attracts hundreds of people from all countries every week and offers an expensive treatment with a "guaranteed" result. The same for a reputed *Siddha Vaidyar* from Madras whose assurances assuage the disconcerted. Moreover, knowing the cure to be within reach, some young Tamils say they are less concerned about preventive behaviour (condoms, abstinence).

The recalcitrance shown towards collaboration appears for the present to be compromised. It is unthinkable that the Siddha doctors encountered would be subordinated to MBBS doctors or health professionals. Any idea of integration in this way under pretext of participation in the fight against the epidemic can only give rise to defiance and reinforce the respective positions. While negotiations are nonexistent, divergent interpretations only serve to increase confusion in the minds and behaviour of the people.

The problem in the time of the epidemic is too serious to be taken lightly. And, there again, it is the Siddha doctor who is likely to gain the advantage. His invocation to life is more enticing than the morbid orations of his detractors. One is in the process of witnessing a cultural reinterpretation of the event. More and more miraculous cures are proposed here and there in the towns of India. Whereas one witnesses the attempted social

liberalization of AIDS by actions of NGOs, some traditional practitioners, who have the power of words, hold the state of seropositivity in moralistic shackles in which one cannot, on the pretence of ascribing meaning to it, consider it to be innocent. A representative of biomedicine is not authorized to claim an unconfirmed medical victory without attracting judicial problems; it is not the same for other practitioners whose legitimacy corresponds to reputation. How then to bring about a reconciliation with the *Siddha Vaidyar-s*?

At present, no one speaks of this. But a time will come when it will be impossible to relegate the subject to oblivion. Will it then be necessary to content oneself with incantatory discourses which, taken in their elegant rhetoric, will only commemorate the patent failure of official attempts to integrate healers in the public health services? Many other things will have to be done. First of all, dialogue. For it is the absence of exchange and their exclusion which strengthen the *Siddha Vaidyar-s* in their position. Then, it would be a question of convincing them of the specificity of AIDS respective of other ailments with which they associate it. Once the problem of AIDS has been dissociated, conventional preventive discourse will no longer be ill-founded and the illusory modes of prevention commended by the traditional therapists can be better controlled. In the future, other essential tasks can be entrusted to them, as for example the participation in counselling and the search for medicines to retard the evolution of the disease.

A contrario, the representatives of modern Siddha establishments are more circumspect and cooperative, insofar as they accept scientific experimentation and dispose of the symbolic and social dimensions of the disease. There is a reputed research centre in Madras where investigations are being made. Certain preparations with a plant basis are being tested, so as not to have to import expensive medicines such as AZT. This is the first encounter between microbiologists and Siddha practitioners. But, the debate has only begun.

TB and AIDS : For Better Integrated Private Medical Care in India

Dr. E.V. Venkatarama Gupta, Director EAV Trust, Bangalore (Karnataka)

TB-like symptoms are quite common in general medical practice

Symptoms similar to those of TB are found among 5 to 10 per cent of the general population. Those clinically suspected of having TB, with TB symptoms such as cough, fever, chest pain and blood-stained sputum, only test 10 per cent positive for TB on diagnosis.

Even the poor usually go to the nearest trusted medical practitioner, as private practitioners are more conveniently located, more sympathetic, courteous and effective than government run services which have inconvenient opening hours, long waiting times, and administer sub-standard drugs. Most of the TB patients (50-80%) first seek help from a private practitioner, and about half of these continue treatment with the private practitioner who first diagnosed TB and maintains confidentiality and provides effective treatment. Upper classes generally do not go to government run services in India.

Initially, patients commence taking the prescribed drugs with great seriousness, continuing until they have gained symptomatic relief. They subsequently begin to resent the cost and inconvenience of following the treatment for the prescribed duration of six to nine months. The pharmacists who supply the drugs also assume the role of doctors. Patients discontinue the taking of one or more drugs after the initial intensive chemotherapy. Moreover, many patients strongly feel that TB carries a social stigma, a sentiment commonly observed in female TB patients. The private sector plays a major role even in the treatment of such diseases as malaria and episodic illnesses of short duration.

Prevailing TB diagnosis and treatment

As time progresses and the TB symptoms become worse, professional help is sought. The most common investigation used in the diagnosis is the chest X-ray. Fifty per cent of the patients are diagnosed by this means alone. Most consulting physicians refer TB patients for examinations of sputum, blood sugar, blood counts and ESR. The test called Montoux is quite common for extrapulmonary TB cases.

Once TB has been diagnosed, treatment usually consists of TB-daily-kits, which have recently been popularized among private practitioners and pharmacists by companies manufacturing anti-TB drugs. The regularity and the completion rate among upper class patients and those who are well-motivated are high. Feedback from a sample of general practitioners indicated that they are really endeavouring to become aware of the proper methodology of diagnosis and chemotherapy for TB and AIDS patients who attend their clinics.

The widespread problem of TB and AIDS in India

It was estimated that three million people were co-infected with HIV and tuberculosis (I.U.A.T., 1993) in 1993, a number which has increased to 5.6 million people in 1996, according to *WHO/TB/96* - 204-1996. Of these, 5.6 to 7.1 per cent annually develop active TB. The relative risk caused by the HIV infection of the tuberculosis infection progressing into the tuberculosis disease is estimated to increase six-fold.

It is estimated that there are one million HIV-infected individuals in India (ICMR), and that 40 per cent of the population is tuberculin positive. About 4 lakhs of people are co-infected with HIV and TB; of these, 10 per cent, or forty thousand, will develop active TB. A study in Mumbai showed that 8.9 per cent of the TB patients were HIV-infected, and that 70 per cent of the female TB patients with the HIV infection were commercial sex workers (Dr. K.C. Mohanthy, et. al., 1994, 45th TB Seal Sale Campaign Souvenir). A total of 559 cases of TB and HIV were reported in December 1993. The chances of HIV-TB infected persons developing active TB increase up to 10 per cent every year, from 10 per cent up to lifetime in persons having only the TB infection (Dr. Mukherji, IJT, 1995).

TB and HIV infection are suspected among clinic patients with the following symptoms:

1. Major symptoms

- Loss of appetite, fatigue, malaise, night sweats ;

- Loss of more the 10 per cent of the body weight in 4 weeks ;
- Chronic fever of more than 4 weeks' duration ;
- Recurrent diarrhoea of more the 4 weeks' duration.

2. *Minor symptoms*

- Generalized lymphadenopathy ;
- Oral thrush ;
- Repeated common infections such as otitis media, sinusitis, pharyngitis, etc.
- Chronic cough of more than 4 weeks' duration;
- Chronic pruritic dermatitis;
- Recurrent herpes.

Clinical diagnosis is made in a patient complaining of at least two major symptoms and one minor symptom.

Refer suspected HIV-TB cases for laboratory investigations:

For Tuberculosis:

1. Sputum smear for AFB (Acid Fast Bacillus) confirms TB when two smears out of three examined are positive ;
2. Positive culture for AFB is more specific ;
3. Biopsy of lymphnodes positive for TB is also more specific ;
4. X-ray of the chest is helpful ;
5. Montaux test will be helpful in recent illness and for children ;
6. CT-scan and MRI are more specific in extra-pulmonary TB.

For AIDS :

1. ELISA (Enzyme linked immuno-sorbent assay): two tests for HIV I and HIV II confirm HIV infection ;
2. Western Blot is more specific ;
3. Virus isolation from culture of lymphocytes is highly specific ;
4. CD4 T Lymphocyte cell count below 250 per mL (micro litre) is highly specific.

Management of TB in HIV-positive patients

The problem of TB and AIDS represents a national emergency. Both diseases are preventable. TB patients with HIV infections will respond well to anti-TB chemotherapy, with INH-pyrazinamide-Rifampicin-Ethambutol daily-kits for the initial three months, followed by INH-Rifampicin daily-kits for five months.

Prevention of AIDS and TB

AIDS is preventable by the use of condoms, the use of HIV-tested blood and blood products and the use of sterilized or disposable syringes, needles and blades.

TB can be prevented by chemo-prophylaxis with INH-Rifampicin daily-kits for all HIV-positive persons for one year, or more if necessary.

Domiciliary care of HIV-positive patients at their homes in the community requires counselling regarding the non-communicability of this infection by way of casual contacts. In most cases, AIDS is spread through multiple sex partnership. This fact must be highlighted in order to prevent multiple sex behaviour and unsafe sexual practices. Injection therapy may be minimized.

Conclusion

It has become clear during various seminars conducted for general practitioners by IMA branches, by the India Association of Occupational Health, the EAV Trust and other NGOs, that many general practitioners want to have guidelines concerning the diagnosis, management and prevention of HIV and TB. This article has attempted to provide such information. Further suggestions from readers may please be communicated to the EAV Trust, 27/8 Cubbon Road Cross, Off Union Street, Bangalore 560 001, India.

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6. WHO *Report/TB/96* - 204, 1996.

Discussion

F. Bourdier: In the course of its information campaigns in the media and through brochures distributed to the public, the Indian government provides information with which to identify the disease. Certain associated symptoms, such as persistent diarrhoea accompanied by pronounced loss of weight, are signs announcing a possible infection by the virus. It is certainly legitimate and necessary to inform the public, but one must still look into the manner in which the latter interpret and reappropriate the symptomatology. A striking aspect, which is to a certain extent found in other countries of the South, is the evident determination of the people to want to identify the disease. Nothing is less tolerable in the time of the epidemic than to find oneself confronted by a mortal pathology which cannot be clearly identified, namely during the asymptomatic period. Each time that I have witnessed preventive campaigns organized by NGOs, the same questions constantly recurred, raised by both men and women: "How to recognize someone who is seropositive? How to distinguish him from others? Are there signs in his behaviour which would disclose his state?". Quite obviously, the search for a certain visibility of the HIV infection is at the centre of the concern of the population. It is precisely there that it is indispensable to be attentive and not give free rein to the popular imagination. One must be clear and not allow any ambiguity to appear: one most certainly cannot identify a person suffering from the virus. Any contrary attempts can be the subject of gross misunderstandings. For example, a person with tuberculosis develops visible symptoms which approach those enounced as indicating the presence of AIDS: thinness, pulmonary problems, etc. However, in a country where malnutrition and under-nutrition are unfortunately frequent, it can prove to be dangerous to assimilate thinness/slenderness and the HIV infection. Such false similarities can give free rein to "brutal" attempts to identify infected people. The same is the case for persistent diarrhoea: how many people

in India suffer from diarrhoea without carrying the virus? It is evident that such a "hunt for the sick person" can only be harmful insofar as it would give free rein to an unbridled stigmatization. The role of a government, of NGOs, is in this regard essential if they do not want to one day see themselves accused of irresponsibility, indeed of complicity in a process of social discrimination which they have furthered.

Human right and AIDS in India

M. Govindan Himalaya Association, Madurai (Tamil Nadu)

Background

HIV/AIDS threatens the health and life of millions of people throughout the world. It potentially affects all of us, whether by actual infection, by the threat of infection, or by the devastating consequences of the infection on our families, friends and communities.

But HIV/AIDS threatens not only health and life, but also human dignity, autonomy and human rights. The spread of HIV illustrates how the disadvantaged in our societies are particularly vulnerable to infection and how they must bear not only the burden of the disease, but also the burden of discrimination based on their HIV status.

The Universal Declaration of Human Rights proclaims that every individual is equal in dignity and rights, including the rights to life, health and non-discrimination. Discrimination, stigmatization and the related loss of human rights increase vulnerability to the HIV infection and AIDS in several ways. The associated problems and issues could be discussed in India in terms of the following categories:

1. screening and testing policies ;
2. problems at the workplace ;
3. blood banking and related issues ;
4. ethical issues in the screening of pregnant women ;
5. issues in the delivery of health care ;
6. some specific patient-related issues ;
7. problems in the implementation of public health policies in prevention and control ;
8. ethical considerations in the field of bio- medical research.

In medical research, it is expected that certain moral principles are to be followed;

- good should be done and harm avoided
- wishes and interests of the clients or patients should be respected ;
- wishes and interests of society and the community at large should be judged fairly ;
- the question of voluntary versus mandatory testing.

Nothing which is done under compulsion will be successful. The role of mandatory testing for HIV in certain specific situations to prevent the transmission of HIV to healthy persons must be deliberated.

For example, blood, organ or sperm donors must be screened for HIV. The question is, however, is it justifiable to perform pre-employment screening for HIV? If the answer is affirmative, testing of whom, and how? Here the question of economic viability arises if testing is to be done in all settings. Is one to test samples or individuals? If individuals are to be tested, to which extent is confidentiality to be maintained? These problems fall under two headings, namely

- voluntary testing versus confidentiality
- mandatory testing versus confidentiality.

Does Section 126 of the Indian Evidence Act entirely respond to this problem ? No.

Section 134 empowers the isolation of an individual in the name of health hazards. Articles 14, 15 and 16 deal with anti-discrimination provisions which control public sector employees, while private bodies are free to behave as they choose. However, the main discriminatory agents in relation to HIV/AIDS are the government authorities and institutions. What is to be done ? Health is not one of the items mentioned in Article 15, which refers to discrimination based on religion, caste, race and sex in military recruitment, prisons, correctional institutions and respective of the mentally deficient where mandatory testing is carried out. Why ? Perhaps in consideration of the effects of drug abuse and homosexuality.

Two distinct issues are the denial of jobs to individuals on the basis of his/her HIV status, and dismissal or isolation should one already holding a job contract the infection.

Mahatma Gandhi stressed that *pulanadakkam* (self-control) is the only way to control the population explosion, not the adoption of contraceptive methods.

Other eminent persons have held that Indian Penal Code do have the potential to guarantee the respect of ethical law, but contrary to this we are promoting the use of the condom, which is a double-edged weapon.

Isolation is sometimes counter-productive as the patients may go underground and not disclose their ailments. Voluntary or compulsory testing can only be successful when total confidentiality is assured. To promote voluntary testing, it is essential to implement long-term measures, such as enacting or strengthening the existing laws which forbid unwarranted testing and the disclosure of the results. Apart from education, counselling and condom promotion, there is an acute need to develop an appropriate legal environment to combat the spread of HIV. Undoubtedly, there is a need to combine forces and work for a positive law which will protect the rights of HIV-infected persons, which is to say the rights of society.

The essential thing to keep in mind is that in the absence of government action, public action is of paramount importance. Otherwise, rights remain only on paper.

In addition, workshops at national, regional and local levels should be conducted for legal, paralegal and lay persons working for the rights of the infected. Consent should be received before testing. Pre- and post-test counselling should be given. Once confidentiality has been assured, steps should be taken to maintain it. Health care personnel should not neglect the legal and ethical aspects of their practices. Access to health care is a human right, and HIV cannot be an exception.

Discrimination and stigmatization against those already infected and diseased, and those at risk of becoming infected, is a violation of human rights. It has been realized that discrimination and stigmatization are always counter-productive in achieving the desired effects in prevention and control. The approach of public health professionals should be to very objectively consider these issues in the right perspective.

Legal aid investigation and human rights for the people living with HIV/AIDS

Accusation and procedures

1 (a) After the pronouncement of Supreme Court of India judgement, the state issued an order to stop the collection of blood from professional donors; but, in fact, the private blood banks depend solely on professional donors, apart from a few exceptional free and voluntary donations from others. A NACO report says there are unlicensed blood banks. Hence, it is clear that human lives are taken for a ride. Ferguson's study (1989) states that 1018 public and private blood banks would be able to collect only 1.95 units, whereas the real need is 4 million units, i.e. $0.59 \text{ hospitals} \times 7 \text{ units} = 4.13 \text{ units}$). Because of this gross shortage, blood banks are forced to depend on professional donors in spite of government instructions. The study suggested that the shortage of voluntary donation and unsafety of professional donations _____ ??? _____.

1 (b) In government hospitals, the patients requiring blood transfusions are advised to get donations from their close relatives. In their absence, the patients with the help of some mediators get blood donations from the professional donors using the names of relatives. They are paid for it by the patient at the back doors. This lapse could endanger blood transfusions. Hence, the system needs critical monitoring.

1 (c) In Judicial courts in Madurai, unlawful and unfair blood traders face criminal trials. To cite a few cases:

a- Drug inspector, Madurai against Grace Kennet Foundation Hospital. Dr. Sam Bose admitted the offence and paid the fine of Rupees 3000 in Judicial Magistrate Criminal Court for blood safety violations.

b- Drug inspector, Madurai against Dr. Anuradha Ramanath in criminal code No 202/96. She was acquitted for technical reasons but, in fact, blood safety was violated and the acquittal was stated to be on humanitarian grounds.

c-. In Judicial Magistrate Court Madurai Criminal code No 551/96 and 552/96, the Drug Inspector Madurai files a case against Algammai Radha, and a hemophilan person files a case against Mahalaksmi and K.R. Jawaharlal, who were convicted for blood safety violation

1 (d) In the above cases the prosecution maintained that the convicts are transacting blood with unlicensed blood banks, which are follows in Madurai surrounding

a- Two Hospital ^{Bank;} cum blood

b- T_{WO} Foundation Hospital_G;

c- A Mission hospital

The above facts clearly reveal that there are unlicensed blood banks dealing with blood without caring for human life. Only a few cases were here.

1 (e) Even in licensed blood banks, the registers of donors and vendees are not properly maintained. The blood may either HIV positive or negative, or belong to the window period. When the vendee/consumer discovers that the blood transfusion has been the cause of an HIV infection, redress can usually not be had because the limitation period has elapsed.

1 (f) Our survey showed that 5 - 10 per cent of the samples organized by blood donation camps was disqualified because of infections, including HIV positive. This disqualification is properly done only in the government sector, but others do not disqualify any samples. This definitely creates room for suspicion as regards the private agencies dealing with blood.

Irregularities and misfortune

2 (a) Article 21 of the Indian constitution states that life is not merely biological, but life in a real sense is with all human dignity and amenity. In 1997, the police registered 182 cases in Madurai, 209 in Periyakulam and 200 cases in Uthamapalayam under the Prevention of Immoral Traffic Act (ITA). The judiciary and the police unlawfully referred the individuals for medical examinations to determine their HIV status, which is unwarranted. For instance, in 1995-96, all the cases of women brought by the Theni police station (a locality well-known for open prostitution along the river Vagai, sixty km west of Madurai) before the Periyakulam court under the Provention of Immoral Traffic Act were referred for compulsory testing.

2 (b) All India Institute of Medical Science and Indian Council Medical Research forcibly tested the commercial sex workers with the help of police. An organization called ABVA protected and alternatively suggested the provision of good quality condoms, human treatment, and pre-counselling. ABVA protested at the refusal of treatment before the Indian Medical Council of Research.

2 (c) In many places (rural and urban settlements), pregnant women have been refused access to hospital delivery after having tested positive, *or on the ground of suspicion*. For the same reasons, a three-month old infant was left unattended and died in a famous hospital in Mumbai. The All-India Institute of Medical Science refused to treat a man and his brother because of their HIV-positive status. An African man faced a refusal of surgery at another hospital in Delhi, in 1994, and died. The same fate occurred to 14-year old thalassemic boy in Chennai. These are just a few examples.

3. The positive result is like a death sentence to a person. Hence, the individual and his/her relatives need emotional and social support. There is professional acceptance that the pre- and post-counselling is very crucial in the management of a seropositive person. But, unfortunately, neither the blood banks nor the private practitioners have any professionally trained counsellors to offer pre- and post- counselling. With the medical practitioners ill-equipped to deal with the behavioural and psychological issues relating to this disease, there is a growing need for a psychological counsellor as a member of the medical team in all the specialized centres providing care for the HIV cases. As there are no behavioural sciences in medical colleges, the health care system will consist of doctor, paramedical, and social worker.

Confidentiality and divulgation

4 (a) the patients/ clients entrust themselves as in secrecy to health service providers. But with little effort one can get the list of HIV cases from the government hospitals and other testing centres which are supposed to maintain their records confidentially. Only recently, the out-patient number of STD-suspected patients was mentioned for test results. There is a chance of social isolation and discrimination due to intolerance attached with this disease.

4 (b) last year (17.3.97) a woman of 40 years, Chinnayee, died as a result of AIDS at Alanganallur village near Madurai. The press exposed the matter and raised alarming issues. Two of Chinnayee's children are still living. The attitude of the press has greatly affected the rights of the individuals (Chinnayee and children). Through such violations of intimacy, the press directly affects the individuals and their family members. Such types of violation are not confined to Madurai, and many similar incidents have been reported in other cities. The news is used as a mere pretext for sensational advertisement and divertissement. There were incidents in which the mother of an AIDS patient was

socially ostracized. In other cases, her children were denied admission to the local schools. The publication of photographs of mother and child furthermore aggravates the suffering of the families and affects their dignity.

5 (a) In Madurai city there are private and government medical laboratories carrying out HIV testing with deficient kits. In the meantime, among the “ HIV-negative blood ” which is transfused, some persons may be in the three-month window period (antigen test not conducted). The United Kingdom, in order to avoid this, follows the “ Polymer Chain Reaction test ”. The security and safety norms prescribed by the WHO insist on testing with two-principle based ELISA tests before confirming positivity. The government supplies only the one-principle based kit. The kit contains 98 samples, and the test is carried out only after all have been used. Instead, kits should be designed to carry out just a few samples so that the testing rate can be improved.

5 (b) On the occupational side, technicians and medical practitioners dealing with HIV are not protected by the state employer. No risk allowance is provided and the remarks about the ELISA kit, or any test kit, are not taken into consideration by the competent authorities. Nevertheless, the professionals who are facing risk of exposure to HIV suffer from adverse remarks by the authorities.

Problems at the workplace

In our target area, we have two persons who were sent back from their workplaces in the Gulf countries because of their HIV-positive status. Due to the social stigma and the apprehension of termination of a job, the positive persons do not reveal the truth. Industries in Madurai have not yet resorted to any compulsory testing, but we have been told that such a project is being prepared. Industrial managers may initiate the compulsory testing at any time.

In the health care system, at least 30% of the medical practitioners are recalcitrant and refuse to treat HIV-positive persons. In India, 80% of the well-functioning hospitals are in urban areas, but 80% of the rural population gets below 20% of the biomedical services.

There are non-allopathic practitioners in Madurai who provide allopathic treatment for STD cases. But, the law implementing authority has ignored this practice. The danger is that such doctors prescribe injections without the basic security. Such quacks with illegal practices at different places in our project area are rampant all over India. They are solely responsible for propagating myths about HIV among the people attending their clinics.

Conclusion

A reputed doctor violates the blood policy and is acquitted due to certain legal lacunae and underground networks. Other reputed hospitals have been sentenced. All these incidents are in violation of human dignity and threaten prevention efforts. Again we, lawyers, suggest that efforts should be taken to determine the facts. Along with the general population, we should raise our voices for new public legislation. Promoting social acceptance to cure the stigma, assuring confidentiality and related informed consent, providing free pre-and post- test counselling are a few basic observations to counteract the crass violations of human rights among the people living with HIV and AIDS.

Discussion

Dr Jaisankar : In India, being an underdeveloped country, the welfare of the poor people is taken care of by the government. If anybody dies, even on the side of the road, the government or the municipality takes the responsibility to do the necessary steps. In the same way, the government hospital provides medical care to any Indian without any discrimination. If there are epidemic diseases like cholera, leprosy, etc., the government undertakes a mass vaccination programme. Whereas in America and other countries, any doctor can refuse to treat anyone. Here somebody can be prosecuted for refusing to be vaccinated against epidemic diseases, insofar as it is considered as a national disaster. AIDS is also an epidemic. Can you shelter, Mr Govindan, under the same law and then implement this totally, without taking into consideration confidentiality, morality and other things ?

Prof. S. Shanmuganandan : What are the positive indications you suggest now ? What do you think we have to do in order to care for private and social concerns? All diseases cause heterogeneous problems such as how it spreads and from whom and to whom it spreads. We therefore have to consider the morality related to that kind of disease according to its social and epidemiological implications.

Vishwa Deepak : We are not here to determine how to arrest HIV infection, but how to take action on the basis of our our experience. Why do you put forward here morality and other unnecessary things ?

M. Govindan : Epidemic diseases like HIV/AIDS come under the welfare of the state. It is also important to discuss how the human rights of HIV /AIDS patients are affected in the society.

Man respondent : Everybody knows well how HIV/AIDS is spreading. In general, any epidemic disease has got some incubation period. During that period, the person may be warranted and may be isolated so as not to infect others until the disease is over or controlled. That is possible only in the case of contagious diseases. We know, in the past, the leprosy patients who were easily identified were sent to a separate place in Honolure. But nowadays, they are living with us and they are not sent to isolated places. Because it is controlled by treatment with the available vaccination and medicines. They need not be warranted to prevent the disease from spreading. But in the case of AIDS or the HIV epidemic, it is very difficult to identify the persons who are infected. It can only be prevented by changing one's behaviour or attitude.

Prof. G. Gurumurthy : The entire population should be made to take a mandatory test in the welfare state. When you surrender and accept the benefits of the welfare state, it means that you surrender also to certain duties.

F. Bourdier : If you were to introduce mandatory testing, just try to imagine what be the reaction of the community would be.

Usha Raghavan : How many of you are ready for mandatory testing ? We can say that mandatory testing is perfectly fine. Only certain categories of the population have high-risk behaviour. We cannot implement the mandatory testing to all. We have to think how far the mandatory testing will be worth while. It is a dynamic process. If the person has high-risk behaviour and the result of the test is negative, the person forgets the risk within half an hour and starts again.

M. Govindan : I think you have totally misunderstood the point. I am talking about human rights. I am not talking about the person's character or behaviour.

Usha Raghavan : Let me finish. I may be involved in high-risk behaviour. Suppose, the result of the test is negative. This evening, I go to a bar, drink alcohol, meet a man and go to bed with him. Tomorrow I may be infected. You mean to say that my health is to be tested tomorrow or later? A government cannot reasonably coerce people on the assumption that they have a suspicious behaviour. I cannot agree to this mandatory testing in either the legal or the health aspect. Because how many of them will come forward even were the health care department to be ready for the testing. We have to be critical about the idea_s behind mandatory testing.

M. Govindan : I am not talking from a medical point of view, but from a legal point of view. The question involved here is about human rights. The constitution and any of our human rights prevent any Indian citizen from having to take this test. But at any time, anyone who desires can have oneself checked under the health care system. The right to be screened under anonymous conditions should be available to every citizen. At present, the common man in India does not have sufficient information about the places where he can go for voluntary and anonymous testing. Worse, such places hardly exist.

Woman respondent : If mandatory testing is preferred, I will oppose it definitely.

Prof. Gurumurthy : Why, in that case, have you already accepted the policy of the welfare state?

M. Govindan : In the welfare state, there are some provisions dealing the human rights of the individual.

Dr V. Jeysingh : Recently I had the opportunity to discuss with a delegate from Switzerland the violation of human rights of HIV/AIDS patients. He agreed that basic human rights are still violated throughout the world. Suppose we wanted screen everyone, we should seek the opinion of the Indian Government which may consult the opinion of WHO. Because in 1989, a bill was introduced in the Rajya Sabha about ethics and law related to AIDS. NGOs and the World Health Organisation made a complaint and fought against that issue. As the result, it was dropped by the Indian Government.

K. Santosh : I read about confidentiality in connection with the pre-marital HIV test. In conservative Indian society where arranged marriages are still prevalent, a number of people are asking for pre-marital HIV testing. Under these circumstances, what will be the position on confidentiality and discrimination ?

M. Govindan : In these circumstances, the pre-marital testing of the two concerned individuals may be possible and the results should be given only to them, not to the family.

G. Gunavathy : The discussion is going again towards mandatory testing. It is better to change the point to be discussed.

Dr Abdoul Hamide : If I may be permitted to share my experience regarding STD patients coming to the government hospitals, let me remind you that in the morning session Dr. Shukla pointed out that we should reveal the test report to certain people. I do not agree with this. We cannot reveal the test report to anybody other than the person concerned and revealing the report of a person is also against the law. In government hospitals, it is usual to send blood for analysis to the laboratory where the technician analyzes it and sends the report to the concerned department. Then the concerned doctor notes the report in the case sheet through which it comes to be known to the laboratory technician, nurses of the department, colleague doctors. Along this human chain, it is already very difficult to maintain confidentiality in the hospital. As someone pointed out, confidentiality is only possible if there are particular provisions to tackle it. Moreover, in certain hospitals, it has been stressed that the report be written on the laboratory registration forms. Sometimes, the laboratory technicians refuse to handle the blood sample. This is also one of the difficulties existing in hospitals in practical life. So the policy- makers should come to real life in order to draw the policy. Secondly, the statistical report indicates that spouses have been infected HIV-positive and we have also seen HIV patients coming with his/her life partner. The doctor can recommend the test. Unless willing, the spouse is not to be tested. If the husband or wife wants to divorce, or one wants to marry again another person, then we can recommend that the test be done so that the person knows. If anyone is curious to know whether he/she is infected or not there must be a mutual commitment. But how to be sure about a real mutual commitment ? By testing, we are complicating one's future life. I am running an HIV clinic. So we are not suggesting that people be screened. But we are doing counselling in our HIV clinics. Revealing the HIV test report leads them to be discriminated against by society. For example, if a relative comes to know about it, the patient may be discriminated against. As the result, the patient who has not the courage to face the discrimination comes to the conclusion to die. These are some points to be noted for further debates on the relevancy of testing.

F. Bourdier : We are aware of social discrimination but the process of self-discrimination should be understood as well. Exclusion is practised by society, one cannot deny this; but individuals - or groups - are also participating in their own discrimination to some extent. This point should be taken into account in further research. To complement what Dr Abdoule Hamide said, in some public and private hospitals, the records of the HIV/AIDS patients with their addresses have been disclosed to scientists for research purposes. It was something very natural for the team of scientists that names, addresses and other details were given and written down in the report. Isn't this, however, a violation of confidentiality? Someone here may enlarge the debate on a similar issue: Mr David Thiagarajan is working in the field of prostitution. Recently, some photos of HIV patients from Alanganallur, a village near by Madurai, were published in magazines.

David Thiagarajan : One day, the police arrested the girls and brought them to the police station. They were ordered to stay there until ten o'clock at night. In general, no girl should be kept in a police station during the night. But they were taken into custody to be humiliated. Reporters were invited to come, and they took photos even though the girls refused. The police did not restrict the photographers, whose photographs were subsequently published in all newspapers. Last month, one of them committed suicide because her photo had been published. To meet an acute financial crisis, she had engaged in prostitution for the past six months without the knowledge of her parents or husband. After having published her photo, she became known to the public and to her family; she was insulted and beaten. Then she killed herself. Afterwards, when I made an attempt to file a suit for evident violation of human rights, the inspector recommended that I not become involved in this problem as it could well turn against me. I was threatened by other people as well.

Karl Sequeira : David talked about confidentiality by giving an example. As far as confidentiality is concerned, some provisions exist only for advocates and not for doctors. Even today, confidentiality exists between a doctor and a patient. But no provision exists on it.

M. Govindan : There is a provision in the Evidence Act regarding a person who has committed murder: there is no need to disclose the matter to the police. The lawyer and the committed party can maintain confidentiality and defend the case. In the time of AIDS, if any provision is available regarding confidentiality in medical practice, it would be better.

Dr Sivaram : The confidentiality between the patient and the doctor is extremely strict. One is supposed to keep all information pertaining to patients confidential. Not only HIV status, but all connected reports have to be maintained confidentially. There is no ambiguity in it.

Man respondent : However, the British and American courts have taken a view that revealing the HIV status of a particular individual is legal in certain conditions.

Woman respondent : We have got a lot of problems in our society. We have various state policies. Everything is to be changed at present. Revealing the confidentiality of HIV-positive patients to others cannot be legal, and it is against any natural justice.

M. Govindan : In the High Court of Bombay, there was a case regarding the identity of an individual who was HIV-positive. As he was an HIV patient, he was sacked by his employers. The court stated that there was no need to identify him. Therefore, he was reinstated by the employer. The judgement was in his favour. The lawyer collective based in Bombay took the case. I can give everyone who wants a copy of the precedence. Then you can have access for any other similar cases in order to support people living with HIV and AIDS.

Social, ethical and legal issues in HIV infection

Dr. Zafrullah ,Khajamalai Ladies Association, Trichirappalli (Tamil Nadu)

The HIV infection is more than a medical problem. It is really a twin epidemic, the first being the disease itself and the second the epidemic of fear which is inherent to the HIV infection. The main causes of this fear are ignorance and imminent death. The social stigma attached to this disease is an additional adversity.

Social problems and human rights

The association of HIV/AIDS with sexuality leads to stigmatization. Acute episodes of illness lead to extreme weakness which, together with the knowledge of eminent death, shatters the emotional and physical well-being of people with HIV/AIDS.

Those who have asymptomatic HIV and know about their infection are subject to intense anxiety and depression, often made worse by self-imposed isolation. This isolation leads to further depression due to absence of a cure, fear of dying alone with pain, loss of livelihood, withering away of ambitions, sense of grief, guilt and denial of status. Isolation also leads to anger, suicidal tendencies, loss of self-esteem. The patient writes himself off and he isolates himself from exposure to facilities for help and counselling.

The people infected with HIV and/or AIDS have the same dignity and human rights as any other person. World-wide, people infected with HIV and AIDS are denied these human rights. There are instances where those who are infected are put in quarantine, imprisoned and forcibly tested. People are being deported and denied entries into countries. There are innumerable instances of removal from services of persons with HIV, denial of housing, schooling and even of treatment and care. The media coverage of HIV/AIDS patients leads to social stigmatization. The major social challenge to this pandemic is to stop these abuses.

Ethical issues

One of the ethical issues involved with HIV is in terms of testing for HIV status. Although this testing, developed in 1985, was an important landmark in the AIDS pandemic, contributing to a slowing of the spread of the infection, it has the negative aspect of possibly leading to stigmatization and discrimination. To partly reduce this negative aspect, there should be specific informed consent of the patient for HIV testing.

Premarital HIV testing

This could not be made mandatory as this practice undermines the confidentiality which is a pre-requisite of testing. But individuals could be encouraged to request voluntary testing prior to marriage.

Laws on HIV testing in India

The present laws in India pertaining to official policy with regard to testing are:

- Mandatory testing of blood/ blood products for transfusion ;
- Testing in higher risk groups ;
- Testing of the new-born of women with multiple sex partners.

Other ethical issues

- Confidentiality about revealing the test results to patients' spouses, employers, etc.
- Exclusion of HIV-positive individuals from occupations involving high-risk practices, for example health care workers carrying out certain procedures ;
- Testing of new drugs and discoveries claimed to cure diseases ;
- Conducting behavioural intervention research, revealing identities and thus exposing people to social stigmatization ;
- Ensuring HIV-uninfected blood/blood products and equivalents are used ;

- Medical institutions and Health Community Workers should be increasingly made aware of their responsibilities ;
- Discouraging professional donors.

The legal aspects

- No fundamental human right should be abrogated merely on the basis of common good ;
- No legislation should transgress human rights and forcibly isolate, incarcerate or quarantine individuals merely on the basis of HIV infection ;
- High-risk groups should not be subjected to select discrimination ;
- Consumer awareness and activism should be developed and encouraged ;
- Resorting to litigation in cases of negligence and malpractice would lead to accountability of medical personnel and institutions.

Dilemmas encountered

- In blood banks the ethics regarding disclosure of HIV status to the respective blood donors is, as a rule, not followed. Does merely destroying the HIV-infected blood units end the responsibilities ?
- If a patient refuses to inform his/her spouse of his/her HIV seropositive status, should the doctor do so thus breaking confidentiality; or, should he remain silent and thus place the other partner at risk? Where does confidentiality end and social responsibility begin? There is a social duty to protect the unwitting spouse from irresponsible behaviour on the part of infected individual.
- The three basic tenants of ethics for Health Community Workers are, according to Dr E.J. Desouza, the ethics of love, truth, and do no harm, which should also be applicable to the patients' spouses, family members, community and society.
- Another dilemma concerns the advice as regards the termination of pregnancy which is to be given to HIV-infected women who have become pregnant, knowing that only about 33 per cent of the babies born to infected mothers harbour the HIV infection.

Discussion

G. Gunavathy : You mention possible testing before marriage if both the partners are agreed. It may be feasible in India. Suppose one of the parents ask either the bride or bridegroom to take this test in the name of the son or daughter, what will happen ?

Usha Raghavan : I think it is not feasible to implement pre-marriage testing because there are so many strategies to divert from the necessary ethics linked with such recommendations. Plus, nobody can prevent someone from getting married. Recently, I came across a girl working in a NGO in Namakal (Tamil Nadu). She is HIV positive. She is also a member of the association for HIV positive women. She married a lorry driver. The man already knew that she has HIV-positive. In spite of that, he married her and, as a result, he also became HIV-positive.

Dr Zafrullah : One should make a start. There is no doubt about it. It is difficult in our society. I agree with you. But we have to make a start. Because nobody knows who is harbouring the HIV virus. So we, as NGOs, should discuss this.

Usha Raghavan : You claim that NGOs have to start. If this is the case, and if it is decided to screen people, how are you are going to manage for the three-month window period? If the person is going to be tested today, what about her activities during the last three months? Again, it is a question of million of rupees, because if the test mania starts, it will be costly. And how to be sure that the decision is really taken by the individual, and not “strongly encouraged” by NGOs ? We can cast light on this fact by telling the people that it is left up to every individual to go for the testing or screening. Again it has fallen to the NGOs to follow them for three months to ensure there is no high-risk behaviour. Then, going again for the testing. There will be no end to the process.

Dr Zafrullah : The window period is our problem. We take the blood from blood donors. There also exist some risks. But do you think that just because of the existence of the window period, you will shut all blood programmes in the country ?

Usha Raghavan : No, I am saying that screening will be too delicate a matter for NGOs to assume. It cannot be borne on the shoulders of the NGOs.

Dr Zafarullah : We are not going to do it as a job. We are speaking of screening to create awareness. When my patients want to get married, I suggest that they go for a screening test before marriage along with the future wife/husband. I do not compell them. My STD patients also receive a similar recommendation. In my point of view, I am creating awareness because some of them do not know of the existence of an AIDS diagnosis.

Usha Raghavan : Creating awareness is absolutely open as far as there is no psychological pressure to influence the person.

Man respondent : A number of NGOs are working in different types of projects. So why do they work not on this? I also asked an NGO in my native place to work on this type of project.

Usha Raghavan : It is not allowed under WHO's policy. This is also not coming under allotment.

Prof. Gurumurthy : In a changing society, marriage has become a private affair between two individuals and not between two families. This is not yet the case in India, where there are two types of marriage. One is a love marriage. The couple loves each other and understands each other. One is also ready to sacrifice anything for love. In such a case, why does one not reveal the identity of diseases if one is ready to sacrifice everything for love? The second type is the arranged marriage. In the arranged marriage, certain things like dowry, family status, property, complexion of the girl, height, weight and so on are taken into consideration. Another important thing is the matching of the horoscopes. Many proposals in arranged marriages are rejected because the horoscopes are not suitable. Why do we not create awareness among parents for screening? If anyone wants to get married to a person, both have to undergo this test.

G. Geetha : One factor that we are not considering in this sensitive issue is that we will never be in a position to know to which extent the parents on both sides influence and coerce the brides. Is there any cultural context of privacy in India which prevents us from restricting privacy to the couple and consequently inducing us to include the close family within the intimacy of the couple? It is doubtful and nevertheless dangerous.

Ravishandran : It will become a major consideration in the very near future. If it happens, we must also prepare an answer along with the secondary school teachers who have to answer their school students. Nowadays college girls themselves raise the question as to how to recognize if the man one is going to marry is HIV-positive or not. We have to be ready to answer this question.

G. Gunavathy : It depends on every individual. It is not from the side of the parents. This is the time to question how many woman have effectively gone for testing, and how many college students have gone for testing? And in which conditions?

Dr Shukla : I would like to answer. I am from Maharashtra State. I have learned that only a few people have pre-marital blood group analyses. More than 50% of the arranged marriages are being checked for their blood groups to determine the RH-factor. From the editorial columns of the newspapers, one can recognize that people are thinking about the necessity of pre-marital testing. That is why I cited this point in my paper. We are now analysing the opinion from gatherings made at the beginning of this year. What should we tell the parents of the bride or of the bridegroom if any question arises from their side? Do we have to get consent or not? In brief, we want to know how to deal with the family.

Ramkumar : I also experienced the necessity of pre-marital testing. We once went to the JJ Hospital in Mumbai for a survey. It was part of the Archam project. We were waiting in the JJ Hospital to meet Dr Malinika, who was in charge of the hospital. While we were waiting, we had the opportunity to meet some young women between 18 and 25 years. We came to know that many among them have been infected HIV and all of them were married. Some of them had divorced their husbands after one year of married life. Some of them were still living with their husbands and two or three cases were HIV widows. When we saw the study by Dr Shukla, we found that the majority of men between 20 and 35 and women between 20 and 25 were infected. It means women are infected at a younger age because they get married at a younger age. In a larger prospective, Indian women do not have pre-marital sexual contact, whereas men are high in percentage compared with their sex counterparts. On the side of the men, there is less social control with regard to their behaviour. So they are generally engaging in pre-marital sex at the ages of 18 to 25 years. In our society a man marries between 25 and 30 years, and the average age of women at marriage is 18 to 22 years. So in general, men acquire HIV around the age of 25. In regard to HIV-positive persons, the incubation period to develop AIDS is roughly 4 to 5 years. Then the couple may be affected by HIV around 25 years. Once the alliance is concluded, one may feel happy for only one or two years after the marriage. With the effect of some clinical diseases, one comes for diagnosis of HIV at the age of 30 years for men and 25 years for women. It is a very gross average but it reflects a trend. In India, because of the high cost of living and the low quality of life, the length of life for HIV affected persons is hardly more than eight years. If a man gets HIV around the age of 25, he faces death before 35 years. The same is applicable for women. Subsequently, a certificate before marriage seems to be necessary in the present disastrous context.

Man respondent : Logically, the argument given may be correct. But the problem is that one who is infected by HIV did not necessarily get it through sexual contact. There are other channels.

F. Bourdier : We again find this tendency to perceive of women as innocent virgins and as a distinct vulnerable group. Mr Gopalakrishnan has undertaken a study of the sexual behaviour of men and women in the area of Coimbatore (Tamil Nadu). Middle-aged married women use younger men and are ready to pay for their service. There are networks among married women to find attractive young men.

Usha Raghavan : Mr. Ramkumar, you are projecting a false profile which reflects the Indian patriarchal tendency in society. Pre-marital and extra-marital sex certainly does not depend on men alone. You are looking at society as you like, in a different way from what it really is. As already mentioned by Frederic, with reference to the information available, women also contact men and pay them to have sex. This reality is not to be rejected by saying that it happens only in the minority sector or among women belonging to high society. During other research, we came to know that this behaviour also exists in rural areas and among all sections of society.

Mariette D'Souza : As you have said, the incubation period of an individual is about three or four years. But I have already seen people living with HIV for more than 10 years with good health and without any problem. So it depends upon the individual's quality of life.

Man respondent : Recently, there was an offer in the matrimonial column of the newspaper " Indian Express ". It was inserted by an HIV-positive bridegroom. Eight women responded. From the subsequent report, it was made clear that the term HIV-positive would be considered like an academic or professional qualification, such as BA, MA, BE or MBBS. You can imagine the confusion! From this, it is understood that little awareness is prevalent among the women. As per a survey in India, it has been reported that 80% of women do not know what is meant by HIV or by AIDS, specifically in rural areas and not in cities. Hence, instead of talking about creating awareness among women, it is better to act seriously in rural areas where uneducated people are found.

R. Angamuthu : I have been associated with the AIDS control programme for the past five years and with the STD control programme for more than 17 years. During that period, I undertook some research studies on HIV positivity in Pondicherry. The problem we face today is that individual and collective counselling are lacking. The concept itself is gaining momentum. Education has also to be given for counselling.

Ramkumar : Rather than group counselling, individual counselling dealing with high-risk behaviour is more appropriate. I have tried group therapy, but it has some limits. In Pondicherry, we have tried this among sex workers and STD patients.

Usha Raghavan : When you speak about high-risk groups, your destination is once again sex workers and truck drivers. Because they are easily available as a target, you implicitly mean that others do not practise high-risk forms of behaviour. In Chennai, we also tried counselling sex workers and truck drivers, because I too am involved in the AIDS Control Society. The target is easy to approach: high-risk groups like sex workers, truck drivers, slum dwellers. But it is a biased approach.

Dr Venkateswaralou : Everybody knows about the story of the women who were rescued from Bombay brothels. About 32 women among them were from Pondicherry. They were also infected with HIV. The Welfare Department tried to rehabilitate them. Among the group, one prostitute had settled in her village where the villagers treated her as an AIDS patient. They misbehaved violently with her. She was obliged to vacate the place. All vessels and other things she used and touched were thrown out. On hearing about this, we went there and gathered some village people and met the important persons of the village. We talked about HIV/AIDS with the villagers and made them aware of HIV/AIDS. It was social counselling. Now the people of this village are aware of HIV/AIDS.

Man respondent : Individual counselling will ultimately be more effective than group counselling.

Woman respondent : Group counselling comes under the health education department, and then it will not be designated as counselling. Counselling has to be done by professionals, and it cannot be done over or across a counter. If it is a single episode, it is not counselling. Counselling is a continuation, a process. It is more than health education and AIDS awareness programmes and it has nothing to do with giving advice.

R. Angamuthu : I have mentioned social counselling particularly in the context of AIDS education. Group counselling may be useful in order to change behaviour. Newspapers, audio-visual media and television can be appropriate for different populations. We have to judge the suitability of the counselling tool and the suitability of the media for each section of the population.

Ramkumar : Who are high-risk groups: the sex workers or the beneficiaries? If your attention is on the prevention of AIDS, you should target more those who are visiting the brothels rather than the sex workers.

Usha Raghavan : This is my fourteenth year in this field. From the beginning, I have insisted that the sex workers, the truck drivers, the construction workers and slum dwellers are not the high-risk groups. They represent four major areas where we have been taking action; the marketing executives, the tourists, and any other professionals do not belong to any high-risk group. Two weeks ago, I visited a primary health centre where condoms are not distributed to unmarried women, or widows, or separated women. To whom are they distributing condoms? The concerned officer replied that these women are not at risk.

Dr V. Jeysingh : I strongly object to this point of view. The WHO has never recommended the distribution of condoms to only specialized people or high-risk groups. Condoms should be distributed to all who are open to risk. Your statement is absolutely wrong.

Karl Sequeira : We are speaking of social counselling, but what about supportive counselling. One should place more emphasis on supportive counselling. For instance, two years back, a HIV infected person was driven out of his village. I approached an NGO and asked him whether the person in charge wanted to see the AIDS patient. Then I went with this person and showed him the patient, who was locked in a separate room. I opened the window and called, convincing the patient to come out to see the NGO who would seek his welfare. He then came out and told the NGO that the problem was not that he was infected by HIV, but the problem was that he was neglected and

insulted by the villagers. He was working at the railway station, but because he was infected, he was sent away and was subsequently sent out from the family. Then the NGO met the concerned people at the railway station and his family members and made them accept his situation by giving moral support for him to live in his village. I consider that process to be supportive counselling.

Woman respondent : I come again to the subject of human rights and its legal aspect. If the person comes for voluntary testing, we just do the counselling and let the patient know about the testing. The individual has been given the right to know about this result. We cannot stop any individual from knowing the result. After having learned the result of the test, many HIV-infected people have tried to kill themselves. What do we achieve from just testing the patient? If the persons approach us for testing before marriage, it is considered to be a mutual understanding. We do not have any role to play in it. That is why counselling plays a major role in helping the individual to understand. In case of the termination of pregnancy, one cannot force any one to undergo MTP.

Man respondent : Do NGOs and biologists have to agree for the termination of the pregnancy of a housewife who gives birth continuously to female children? It cannot be their concern. Doctors should not trespass their role with regard to the epidemic they cannot control.

Role of Social actors in Prevention of HIV/AIDS

K. Santosh, Researcher, ANRS Project, Chennai (Tamil Nadu)

The government confirms that the epidemic in India is expected to wreak a greater havoc than would be assumed from indications as to the size of the population engaging in risk behaviour, especially the heterosexual mode of HIV transmission. The low level of the standard of living and inadequate health care and its delivery system in India create a particular vulnerability to this epidemic which is extremely disturbing.

Moreover, the visibility of a few AIDS cases, and the non-visibility of the larger pool of infected but as yet asymptomatic cases, makes for a classic "tip of the iceberg" phenomenon convincing the public and policy makers of the severity and grimness of the situation. The available data regarding the HIV/AIDS epidemic at both national and state levels are biased by the choice of specific risk groups covered by NGOs and government bodies. However, there is a proportionate risk in the general population itself.

The data collected by the government relating to HIV/AIDS were primarily from public hospitals which are creating a class bias within the country. The information derived from this data also exhibits the problems inherent in the statistical reporting system of the country which is judgmental, lacks uniformity across the country, and tends to be erratic. In support of this, I could recount a situation where a counsellor working in the STD Department, General Hospital, Chennai, was asked to give counselling only to illiterate and lower class people. Does that mean that the middle class and the so-called upper class were considered to be well aware of STD problems? Does this type of classification not represent an obstacle while bringing out data or information about the epidemic?

Both the government and NGOs are utilizing the statistical information derived through methodologies which lack the basic interpretation of the reality of social dynamics in relation to the epidemic. As a result, most of the programmes of both types of organization lose their value when actually reaching the population.

The very fact that the epidemic should not be solely viewed in medical terms, but should also take into account the human aspect concerning individual attitudes, practices and changes in social and cultural systems, calls for the involvement of social research. My paper attempts to examine the importance of co-ordination among these three social actors, namely the social researcher, government bodies and NGOs, in the prevention of this epidemic.

I would like to put forth my views by casting some light on the problems in co-ordination among the above-mentioned structures by relating my experiences while working with an NGO, in particular with regard to the preparation of a project proposal for a specific community, which turned out to be a complete failure.

This NGO focused on HIV/AIDS and concentrated more on the heterosexual mode of transmission, while working with different communities, particularly with prostitutes and youth in slums. The aim was to promote safe sex, rather than to condemn sex. In the initial phase, we were doing more awareness programmes, with the help of our own methodologies which were designed by our field workers and were meant especially for this population, without a proper understanding of their problems. The objective of this NGO was to raise the level of condom usage among the target community. This was

because the evaluation of NGOs by the government bodies was on the basis of their distribution capacity of condoms.

The prevention programmes were started by highlighting data relating to persons infected in order to create an awareness among the people and raise their level of seriousness towards this epidemic, so as to possibly be effective in changing their behaviour (although this was still an assumption). The basis for our NGO targeting a community as a high-risk group was the data collected from an STD clinic in a government hospital in Chennai meant for facilitating the treatment of STD; this clinic was adopted by us. As the patients were comprised of construction workers from a nearby site, a medical camp was organized. And, as there were some cases detected, the conclusion was that this group needed an intervention programme focusing on STDs and HIV/AIDS. We immediately started the prevention programmes by distributing condoms and forcing them to go for STD treatment. Here I wish to point out that the authorities of the construction site played a role by forcing their employees to attend the camp so that they could avoid medical reimbursement expenditures.

Funding having been of prime importance at that crucial period, the project proposals, in order to get funding, conformed more to the guidelines set by the government funding agencies than to the requirements of the community. The guidelines thus prepared called for quantitative rather than qualitative action. There was another dimension which evolved subsequent to the camp; even though our camp had helped to learn about the community's health status, it created a number of serious problems within the community. Some workers who had STDs were harassed by the other workers, as they had misunderstood that the STD patients had contracted HIV. This situation arose as a result of our earlier visit to this community when we spoke about HIV/AIDS. Therefore the outcome of the study was irrelevant.

Here I want to make it clear that this was not a problem of our making, as we had studied the community according to the proposal guidelines put forward by the government funding bodies. Can we say that NGOs and government bodies are solely responsible for this situation? Would not the involvement of a social scientist bring about a change in the existing scenario?

Now let us examine each of these actors and their contribution to the prevention of this epidemic.

The social researcher

As of today, research has been considered in scientific circles to be an exclusive privilege of a special class of intellectuals. Though this may have some validity, there is an increasing need in research in the social sciences for field workers to improve the quality of their action. Social dynamics play a vital role with regard to this epidemic. But until now, approaches dealing with social issues have often been compartmentalized and there has been no overall structure through which information could be circulated or a debate encouraged. This is especially the case between research bodies and organizations in the field of AIDS. In the Indian context, the value of the social scientist has not been properly appraised, as this type of activity was only concerned as a preliminary step in the implementation of the project.

From the very beginning of the epidemic, the epidemiological aspect of the HIV virus has revealed a series of categories of the population which are particularly susceptible to the virus, such as prostitutes, migrants, long-distance drivers, women,

young people, etc. These categories have been indicated by collected data, and the focus of government health programmes and the NGOs trying to implement such programmes has been on them.

The social scientist could play a major role in defining which actions would be suitably adapted or directed in order to fight against AIDS. The social history of the disease shows clearly that categories of the population designated as being particularly vulnerable and at risk are being accused of spreading the virus, all the more so when their social status is unfavourable in the first place. How can we ensure that, by insisting on the need and urgency for new types of intervention, we do not end up accusing or stigmatizing people?

Interestingly, researchers in India have noticed that there has been a tendency for HIV/AIDS intervention programmes to be based on writings and research done in Western countries which have been adapted by Indian governmental bodies and NGOs.

Social activists (NGOs)

In AIDS prevention and control there is a global recognition that the involvement of NGOs is of great importance. They became popular and notable among the public by revealing the bureaucratic procedures and approach of government programmes. As most NGOs are not bureaucratized, they show a tendency towards innovation and experimentation in community intervention, and exhibit flexibility and an ability to change after gauging the needs of the people. These qualities, however, correspond to small and medium-sized NGOs. The other advantages of NGOs is that the methodologies devised are low cost, and they tap local human resources with the commitment and ability to work co-operatively within the community. These aspects are of great value in relation to HIV/AIDS intervention.

As most of the NGOs are from outside the community, they are in a position to implement the HIV/AIDS intervention programmes, sometimes linking them with other programmes. This can, however, bring a negative effect to the whole programme. For instance, most of the awareness and prevention programmes target so-called high-risk groups by highlighting their sexual behaviour in relation to the general population, and this becomes one way of stigmatizing and ostracizing them.

Government bodies

The welfare of society in general, and the success of HIV/AIDS prevention in particular, depends on the action and policy of government bodies. It is, therefore, suggested that the formulation of any policy should promote the co-operation, confidence and trust of the people by protecting their basic human rights and dignity. It is a well known fact that certain actions can be taken only by the government, as it is the official authority for controlling this epidemic. Government agencies seem to be primarily focusing on medical aspects like cure, rather than on prevention and care.

The main grievances against government bodies expressed during interviews with some researchers and NGOs pointed out the ineffectiveness of the National AIDS Control Programme, which is considered to be too centralized, too vertical in structure, not sufficiently integrated with the various providers of health services, and not caring sufficiently for the patients. In many cases this is an accurate assessment, but we should not simply look at the symptoms without checking the underlying causes and the general

context in which these problems are found. The question is thus whether the approach taken by government bodies in preventive measures against the epidemic is effective in the context in which the programmes have been set up.

Need for collaboration; a change of approach

Social researchers

Social researchers must primarily help to understand the dynamics underlying the advance of this disease and the process which tends to accentuate or to mitigate its consequences. First, social scientists must accept that the situation urgently calls for the provision of knowledge needed in order to devise action strategies suitably adopted to the specific sociocultural and socio-economic conditions.

Moreover, the initiative of researchers must be based on in-depth studies in order to provide solid points of reference, and their studies should reach accurate conclusions much more quickly in a much simplified manner in order to achieve effective intervention against this epidemic.

NGOs

As far as action in the field is concerned, most are involved in information, training and education, either at a fairly general level (information on the disease and its transmission), or on a specific theme (such as condoms). In some special cases this information is targeted at the general population and in others it has a more specific target group. Here, NGOs should understand the criteria from which a particular feature of a target group is studied and defined according to the social environment in which the action is intended to have effect. As AIDS very quickly mobilizes an attitude involving stigmatization and ostracism of sufferers in all societies, it is necessary to be extremely careful when defining a target group, and ensure that individuals are not differentiated within a population by virtue of the fact that they are being singled out to receive information and are thus the only group concerned with the disease.

As there is already a network existing among the NGOs working against this epidemic, action oriented issues should involve the researchers, which would facilitate the sharing of information and encourage debate concerning the social and human dimensions of the AIDS epidemic on a common platform.

Government bodies

This is the sole authority in charge of policy-making and also of the supervision of the various bodies involved in implementation. Government authorities should take into account the importance of the other two bodies, namely the social researcher and the NGOs, while formulating the national policies guidelines for NGO action. The government should provide a common platform for debate and action on issues relating to intervention in the HIV/AIDS epidemic.

We can conclude, on the basis of the above analysis and discussion, that in the present context there arises a dire need for co-ordination among the three organs to fight the epidemic effectively.

Discussion

Dr P.K. Das : You have rightly pointed out very important issues and most important is that you have re-emphasised the need for social science research. Nobody denies that without the social dimensions, no control by only medical knowledge can succeed. You have also pointed out that we are only looking at the tip of the iceberg by only selecting the STD clinics which entails a lot of class bias. Now the impact of the study is the behaviour of the patients. Here in Pondicherry we have known patients who once having come to know that they are HIV positive do not turn up again. When they die it is just recorded as death due to some unknown causes. You also pointed out that the government programmes are inadequate. You cannot simply say they are inadequate and the government alone cannot be blamed. Because health-seeking behaviour itself has to be changed and the expectation of the people is also too much, although we know that we can do nothing. Once you get the HIV infection, what health care intervention can you expect ? Some patients think that going to the hospital will cure them. The role of NGOs will probably be to educate them that once they are HIV positive, there is very little chance to be cured and that is why prevention is better than cure. Don't expect miracles from the government. It has been criticized for long but try to imagine the political, economic, logistical and sociocultural constraints the State is facing in a country like India. You also said that some action has to be initiated by the NGOs. We would very much like this august gathering to know what specific action that you were speaking about. Why should the government provide the platform, as you said ? Why shouldn't the NGOs make the platform ? They are the right persons to communicate with the society and they should take the lead and provide the platform and ask the medical person to work as a resource person. If any medical information is required, we will be very happy to provide it.

Saraswathy Sankaran : I congratulate the presenter, it was a very meaningful and comprehensive presentation. I just want to make one remark. I am the director of a research/action oriented NGO in Chennai. In my experience, the NGOs and social scientists need not be isolated. The NGOs' programmes are effected through regular evaluation, as you have shown. So I don't think we should compartmentalise the two. They should be together.

Shyamala Ashok : Another suggestion : when we try to implement some project, it is better that we co-ordinate with the government in some form or other. I would say in many ways, because it is hardly possible for us NGOs to sit on one point of the seat for ever and ever. We sort of do things that the government is unable to do, for instance, we work with certain groups the government cannot work with at that time. Maybe the platform is ready for the NGOs to step in. Ultimately, I want to stress that we have to co-ordinate with the government so that once we go away, the sustainability remains.

Dr V. Jeysingh : I also agree that the statistics available with the AIDS control society and other areas are inadequate. But, unfortunately, the NGOs take only the statistics available from that source. Perhaps the TNSACS can provide funds to one NGO for compiling the statistics from STD clinics and from wherever they are available.

Usha Raghavan : No, it is not possible for the TNSACS to provide funds for the purpose of getting data-base information on HIV prevalence and incidence. Particularly, there can

be duplication of the number of cases. The case can be reported in the government general hospital, the case can again come to an NGO for STD treatment. The patient may go to another city. So we cannot make proper statistics, there can be a lot of duplication and overlapping.

Dr V. Jeysingh : This can happen in government hospitals. Because one is not satisfied with one hospital, one will go to some other hospital. We can think about it. If not from TNSACS, one can get funds from some other foreign agency and can compile the statistics.

Dr Shukla : What I would suggest concerning this paper is that social science is definitely important. But what we find is that when most NGOs undertake work, they do not recruit any social scientist or any social worker in their area of work. If they adopt one person as a consultant or an advisor from the social sciences, then their work and presentation will be superior. Today what happens is that everybody comes out and wants to form an NGO without having any base or knowledge or understanding of the social sciences. So it would be ideal for all NGOs to adopt one social scientist or social worker who is trained in social work. That would give a better perception and understanding about the social background to all the NGOs. Most of the NGOs do not have any such person on their panel.

F. Bourdier : Theoretically yes, but practically this is not realistic. For instance, in Chennai there are more than 300 NGOs working in the field, but I don't think there are more than ten social anthropologists.

Mehboob Dada : What I have recently seen in Kerala is that the State AIDS Cell co-ordinates a meeting of all the NGOs at regular intervals and provides as well some platform to initiate collaboration amongst them. It generates a voice and information and intelligence to the state authorities about what is going on in the state through the collective experiences of the NGOs. So perhaps this is a forward step that this seminar can provide to TNSACS or the Pondicherry State AIDS Cell. You come together at regular places and it should be about information sharing. It should be about dialogues and about learning out of experiences. Such meetings should also be about social scientists and based on the research findings, and findings of the NGOs could concern how we hear about the progress made by the State authorities with relation to what is going on in the state and generally provide a whole picture of what is taking place.

John Dalton : I think it is the government which should say that the NGOs can have a dialogue with the state and encourage them to do so. In each district of Tamil Nadu, the district collector is the chairman of the district AIDS advisory board committee. NGOs are eventually represented on that committee. If a good NGO is not already represented, then as NGOs we should make sure that we do receive representation. We must not only talk about how NGOs can either supplement or co-operate with the government work, *we must do it*. It is no good working in isolation. And if collaboration, or at least networking, can be made possible at the district level, it would be useful. We find that the government lacks strategies to train even their own staff. So they ask the NGOs to provide, for instance, training for nutrition workers. As has been said, NGOs should have on their staff list a sociologist, social scientist or social workers or any relevant person who knows the job. NGOs have got to be

a little bit professional to obtain so-called credibility. And the trouble is that people are knocking NGOs; some of the NGO bashing is quite valid, because we go in there without knowing what we are doing. We think we are NGOs and we can do anything. But I think this is a tremendous mistake : we must be professional. However, we don't need to have the best specialists. As you said, in Chennai there are less than ten social anthropologists. We don't necessarily need such honourable people. We just need to train people and generally the effect will fare well.

Usha Raghavan : Mr Dalton, one of your statements was that the AIDS Cell should call for regular meetings of NGOs. We can call the NGOs to a common platform, and we have already done this, but just the NGOs funded by the TNSACS. But what about the other NGOs funded by other agencies ? They will be not able to participate and share their views. Even if they are called, they would not be interested in attending the meetings. And whatever the reaction, we do not have any exhaustive list of NGOs working in the field of HIV/AIDS in Chennai.

Dr Abdoul Hamide : I understand the intricacies and problems which we face when we start putting our heads together to make a network. But is it possible to have a common body for the NGOs ? I was in France last year, where they have the Centre for Research and Prevention of AIDS. This body has all the information concerning what is going on in France in terms of research activities. This body makes representations to the government and gets funds.

F. Bourdier : A major problem in India is that the bulk of the studies undertaken are not available, even those which have been conducted by the state AIDS Cell. They are in possession of some studies, but nobody is allowed to consider them because the subject is too sensitive. Research studies become a political issue. The drawback is then twofold : on the one hand, there is no possibility of control and criticism of the studies undertaken in terms of methodology, inquiries, etc.; on the other hand, what is the need of a study which becomes highly confidential ? In the same way, NACO conducted a few years back a study all over India in various districts to learn about sexual behaviour and some other crucial points in relation to AIDS. The work has been done and was published somewhere for a very limited number of persons. Apart from them, nobody knows what the content is. The irony is that the findings are supposed to have been a basis for the guidelines of the prevention policies. There is a problem of dissemination of information. We are not doing research for ourselves, we need to submit and to present our research to others, not only to be called into question, but to inform others about our work.

Dr P.K. Das : I must bring the discussion to and end. All the participants have raised very valid points, and I am glad that you say there is a problem and that where there is a problem, we have to find a solution. Someone raised a point about estimation. No estimation is available. A guessed estimation becomes the best estimation, like something is better than nothing. When we say conflict, it does not arise from the part of one person. We cannot say the government is bad or NGOs are bad. There are good and bad NGOs and governments. The only problem is communication skill. When I go to the government, I also work as an NGO because ours is an autonomous body. Whenever our research finding has to be implemented, we do so through the government. But initially, when I started, I also thought

like the NGOs are thinking, that the government is doing nothing. But then the government said, take two districts and start implementing your integrated health programme related to malaria and vector born diseases. When I started working, after being confronted with so many difficulties, I realized that it is very easy to point at somebody. Someone asked why the government does not provide a platform. Why should an NGO not provide a platform ? NGOs can organize a meeting, and wherever there is leadership they can pull together. Everybody should contribute something, whether government or NGO. Let us not argue as to who should do what. Everybody has to contribute something and exchange views. If there is no communication among the three agencies Santosh mentioned, we cannot do anything properly. And we definitely cannot communicate with the society.

Awareness and Prevention Messages through an IEC Method : Perception and Learning from the Feedback of the Chennai Public

By Mrs. G. Gunavathy, ANRS Project, Chennai (Tamil Nadu)

My paper is a feedback on the perception of the public of Chennai of the awareness and prevention programmes, especially the IEC materials which propagate specific messages in various locations of the city. The IEC materials that I have used for my study are the kind of posters which are supposed to be of benefit to the people coming from outside Tamil Nadu. The materials comprise a set of posters which are kept at a very vital level.

We all know the government of India has set up a separate organization apart from the Ministry of Health, namely the NACO (National AIDS Control Organization) in order to control the rapid spread of the AIDS epidemic. Under the purview of the NACO, each state has an organization or a cell created for the sole purpose of spreading awareness and preventive methods. These organizations have evolved numerous strategies and methodologies using various tools to spread such messages in their respective states.

A study was conducted for six months in 1997 in the city of Chennai to test one of the tools of the IEC method, as the Tamil Nadu State AIDS Cell calls it, which means Information-Education-Communication method. Selected for the study were the numerous posters with pictures and slogans and texts devised and created by so-called IEC specialists for the purpose of spreading awareness and preventive methods. These posters and billboards have been placed at various locations in the city and all over the state at such places as highways, hotels, public transport (buses and trains), hospitals, government offices, road meridians, market places, etc.

The methodology used was a personal interview along with a questionnaire and a set of the posters as its annexes. The questions related to how the sample came to know about the epidemic, what his perception of the epidemic was, and his basic knowledge about preventive methods. Apart from that, questions related to the understanding and the perception of the posters shown.

The sample was 100 in number, and was divided into four groups, namely married men, unmarried men, married women and unmarried women. All fell under the age group of 16-35, which could generally be considered as the more sexually active age. It was also seen that the person was spatially mobile and educated up to the secondary school level. The interviewed persons were mostly comprised of construction workers, cooks, truck drivers, casual garden workers, canteen workers, employees of export garment and leather industries, sales people, people staying with relatives admitted with prolonged illness in hospitals and people staying in hostels for further studies, to name a few.

To give an understanding of the situations and conditions under which the study was conducted and under which the interviews were conducted at various organisations and locations of the city, some experiences are shared here.

Context for undertaking the research

In export garment and leather industries

Having come to know that there were many spatially mobile people working in these industries, it was decided to interview some people there. In one particular industry, the supervisor of the shop floor was very co-operative and gave permission to conduct the interviews, but as the interview was in progress, the lady in charge of the employees of the shop floor became very sceptical about the pictures shown and tried to stop the proceedings,

saying that the girls would be spoiled by seeing these pictures and that they might start discussing sex among themselves, which would be bad. Despite having argued the matter, after having collected a few data, the interviewing had to be abandoned.

At another place, the supervisor insisted on supervising the samples while they were answering the questions : as you can imagine, this caused a lot of discomfiture and embarrassment among those being interviewed, and only after repeated pleas would the supervisor leave. Although the supervisor was senior to her boss, and also tried to explain that the posters were found everywhere and that there was nothing wrong in showing them, the lady above the supervisor would not listen and she finally put a stop to the interview.

Among Truck Drivers

Truck drivers at lorry booking offices near Mount Road were chosen to be interviewed and when approached, the office attendant readily allowed interviews to be made with any of the available employees. But, once everyone came to know that the questions related to AIDS, they all started slipping off, even running away, and had to be persuaded to answer. They resorted to crowding around and teasing the person being interviewed. Some of them pointed at other persons, saying they had the habit of going to CSWs and had to be questioned. When they saw the posters and heard the questions, some truckers said they were not interested and some said they would have nothing to do with this kind of questions and ran away or got into their trucks. I could not run behind them. Of course, being a lady, there was a lot of crowding and giggling around me. Nonetheless, a few of them were very frank in talking about their sexual behaviour in a very loud voice without any inhibitions and with total disregard of the people standing around. I, however, tried my best to conduct the interviews separately whenever it was possible.

At a Seasonal Sale

Here, the people were very enthusiastic and at the very mention that the interview regarded AIDS, they became very eager and began crowding around me, giggling and teasing, and persisted in answering in a confused manner. A few of them, however, ran away when they were approached at their seasonal sale. Chennai being a cosmopolitan city, people come from other states like Haryana, Rajasthan, Gujarat, and conduct sales in various halls in the city. It was also interesting to know about them, even if they were not included in the sample.

At a Construction Site

The man in charge of the construction site wanted to be the deciding authority on who should be questioned and who should not. But after a lot of persuasion, he allowed us to choose the persons according to our specific criteria. Among this population, the conditions for our inquiries were quite good and comfortable in comparison with others.

At a Ladies Hostel

The warden insisted on going through the questionnaire and the annexes, and finally argued that the pictures were very explicit and refused to allow the interview to be made, even after she was told that the posters shown were visible everywhere. But the girls staying there readily co-operated when spoken to outside the gate of the hostel. The warden said the girls

staying in the hostel were staying away from their families and they would get spoiled if they saw such posters and answered questions on premarital sex and dangerous slogans like the one I was presenting. She also asked what the parents would think if they came to know that their girls are allowed to give such interviews : “ What are you trying to say, that our girls are indulging in sex, is that why you want to interview them ? ”, was one of the most common statements. Another was, “ They are all very young, some unmarried, so I do not want this to be carried out here ”. Most of the wardens protested, irrespective of our justification.

Reflections from the research

Some ladies staying near the General Hospital which houses the STD and AIDS patients ward also exhibited lack of awareness and also talked about immoral sex trafficking near the hospital complex.

Another interesting observation was that when the people were questioned in isolation, they were very forthcoming with their replies and talked about premarital and extramarital sex without any inhibitions. From this it is evident that talking about issues relating to sex is still taboo in society.

Through this study the extent of non-awareness and misconception was evident and the misinterpretation and misunderstanding of the posters shown could be concretely assessed. Some of the posters were understood totally contrary to the meaning they were supposed to convey. There were also strong objections to the posters depicting women as the vectors of the spreading virus.

The people interviewed complained that they could not understand the language as it was of high standard (either Tamil or English). The posters had rhyming slogans with not so easily understandable words, as was pointed out by many, which was why they could not construe the meaning of the slogans correctly. The posters in English were again totally misinterpreted. They were only trying to comment on the picture and not the accompanying text on the poster, as they could not understand the vernacular medium. Some posters were understood totally contrary to the meaning they were intended to convey, like the poster with the four monkeys⁵ where the fourth monkey is hiding its sexual organs, depicting the message that one should exercise control over their sexual urges. Without reading the accompanying verbal message, people simply say that the poster says not to urinate in public. There is also a poster which depicts moths being drawn to a lamp denoting the idea that you should not be attracted to danger (sex). Some said that the poster is wrong because the disease does not spread by way of mosquitoes, while others said that it does spread by mosquitoes.

Generally, people are not in a position, or do not want, to read what is written on the posters, even when I was showing the posters to them and asking them to take their time to read, look, and tell me afterwards what they understand. This is the kind of observation which shows how the general population interprets and thinks. Communication specialists have to properly express the messages with the picture itself. A discourse is frequently ambiguous with posters put up at various places. No one has the patience and the time to read through them.

The terminology for STD, namely (*paalvinai noi*) and HIV were not understood by many interviewees. Another interesting phenomenon was that many could not understand the term condom. They traditionally called it *nirodh*, which is in fact the most popular brand name of condoms thanks to the Family Planning Scheme of India and its propagation of *nirodhs* as one of the methods. Many could not recognize the picture of a condom, although they were aware that the preservative was one of the methods of preventing STD and AIDS. Also, there were no posters or methods available to create awareness on the usage of the condom. A question on the methods of preventing AIDS was asked and a number of persons, both men and women, replied that it was only by following an orthodox or a moral life that prevention was possible. Our question was an open question with ultimately a multiple choice question whether AIDS can be prevented by following an

⁵ A fourth monkey showing restriction on sex has been added to the traditional three monkeys-symbol of Mahatma Gandhi request for the withdrawal of senses.

orthodox life, receiving injections (of the traditional healers, doctors), using a condom etc. for which they chose orthodox moral life to prevent AIDS. Some of them were aware of the condom as a method of prevention, but quite a few said the *natu vaidyar* (local healer), the quack could cure any disease, as they have had experience of curing various STD and resulting skin rashes in their genitals by means of their medicines. This belief in traditional treatment was observed particularly among the group of truck drivers. For them, this kind of *pombala seeku* could be cured by *Siddha* medicine. They very frankly admitted having contracted an STD and being cured by the *natu vaidyar*.

The people knew the term condom when translated in Tamil as “*aanurai*”, but the interviewees could not recognise the picture of one showing its effectiveness as a method of prevention. They say if you use *aanurai*, you can prevent AIDS, but when they were shown a picture of a condom they asked : what is this ? People (mostly men) complained that there were also no posters demonstrating the method of using the condom and how to identify a proper one from an unsuitable one. Apart from the comments on the annexes, other questions were asked, like whether there were any other diseases which was worse than AIDS. Many listed hepatitis, cancer, chickenpox, etc. as deadlier, because they had seen people die of these diseases, but they had not seen anyone dying of AIDS. Some commented that AIDS was just a rumour spread by neighbouring countries, like China and Pakistan, with whom India did not have good relationships. A few (nearly 5%) did not believe in the existence of the disease.

When asked about the categories of people whom they considered more vulnerable to the disease, the answer was mostly lorry drivers, prostitutes and college students, while some said hospital workers, foreigners and slum people. The fact that many of them mentioned the category of student is interesting insofar as the bulk of the interviewees did not belong to this category.

The interviewees were also asked in the course of the conversation, if they had any doubts regarding the epidemic. Many replied in the negative, saying they had no doubts, although they had several misconceptions concerning the disease. One interesting question raised by the people was if AIDS did not spread by kissing, how could it spread by intercourse, as there is no blood involved during intercourse ? The argument was that the saliva was also a human secretion, as is the substance (sperm) involved during sexual contact. It was felt that many people had this kind of hesitancy. But no one came forward to pose such questions, although an opportunity was given to clarify any doubts. Although it is evident that there was a fair awareness of the existence of the epidemic, the alarming fact is that there is simultaneously a particular lethargy in the society concerning the disease. This is due to the general trend of identifying a particular group/category as the high-risk group, namely lorry drivers and women in prostitution, which causes the common man to think that he is not at risk of contracting the virus.

Our study shows the lack of research at the grass roots level and a lack of planning when evolving a methodology for spreading a message which should reach every individual of society effectively. Especially when it involves a lot of expenditure. Reports say that about three crores (thirty millions) of rupees were expended to formulate these IEC methods, which works out to 50 paise per head, as the population of Tamil Nadu was approximately six crores in the year 1995. There arises an urgent need to use research methodologies for pre-testing the tools before implementing them.

Thus the feedback of just one of the IEC tools provides a picture of the existing level of awareness and misconception relating to other preventive methods. Ironically, Tamil Nadu is supposedly, according to statistics, the state with an awareness reaching the greatest population, and the city of Chennai has the maximum number of active NGOs involved in one way or the other with issues relating to the epidemic. I conclude on this note of grave irony, stating that my research is not over in the sense that I am presently undertaking the same inquiries among the upper-middle class and upper class sections of society..

Discussion

Saraswathy Sankaran : You have showed a picture of a condom to the people during your inquiries. Did you show them an actual condom before asking questions ?

G. Gunavathy : No, even while showing just the picture, I had many objections from the public. Do you think taking a condom and showing it around would have been easy ? The question of feasibility and acceptability arises. One cannot imagine what would happen. Anyway, it was not my purpose. Actually, I wanted to obtain feedback on what the IEC wants to promote with the help of the pictures and stickers intended to increase the awareness of the condom in the context of AIDS prevention.

Edward Laurent : Then how do you think that we can promote awareness of the use of the condom through pictures ? How can it be accepted by the public ?.

G. Gunavathy : I think IEC, if properly done, may be very effective in reaching all the strata of the society. The materials are practical as well : you can easily propagate the messages through them, even to the remote areas. Because it is not easy to carry your TV, radio and loud speakers and spread similar messages. This material can really reach the people, so it must be exploited to the ultimate level to provide all the awareness we want to create. It is not that someone has to stand next to an explicit picture of the use of the condom. You can just put the poster in a vital spot or a public toilet and ensure nobody removes it or, if it were to be removed, replace it. That at least ensures that people can see them, even if people cannot talk about or demonstrate condoms in person to the public. I do not maintain that IEC is sufficient in terms of social and individual prevention, but it represents one step forward.

Dr P.K. Das : Who made these IEC materials ? This is another point to highlight. In India, the wrong people always do the wrong job. When we create some material, we think in terms of our own logic that when we can understand the material, all the people reading the texts will understand in the same way. In Indian society, talking about sex is taboo. It shows that the IEC materials are not of the quality that they should be. This problem can very easily be solved if we address the problem to a group of specialists. If you approach an advertising agency, they will produce good methods and convey the message in a very clear manner. No one has time to read, you said. But I want to ask Mrs Gunavathy if she tried to win the confidence of the persons before getting the interviews ? Then the results will have some relevance. Another criticism : why do you all go to the low-income groups ? Because they have no choice. Why don't you try questioning the affluent class ?

G. Gunavathy : That is what I plan to do. One criterion of the sample was that they should not be educated more than ten to twelve standard as I wanted to see how people who are uneducated or educated only up to this level perceive these posters. In that case, the people holding jobs below X standard were manual labourers. I had no choice but to interview them.

Dr P.K. Das : If education was the criterion, you should have had an educated group as a control group.

Prof. Gurumurthy : I have two comments, one on the posters and another on the research methodology. As Dr Shukla mentioned, there is an acute need for social scientists and other specialists in our country, but there also versed in communication through certain media, for instance body language, pictures, slogans. But, unfortunately, India is a very big country and there is a great diversity in culture and language. What something means in Marathi may mean something else in Kannadiga or in other languages. The materials you showed were prepared in Delhi at the centre and we don't have the freedom to adopt them to local conditions. At the national level, they prepare posters and these posters have to be distributed : politics and money are involved in it, and when these materials reach the local level, like the Tamil Nadu level, you have to look into the local culture.

Usha Raghavan : No, there is not only a central agency preparing these materials. They are created at the state level only. But these materials were prepared two years ago. We have not recently created any such materials. So I cannot comment on this. At that time the advertising agency was the only agency. There no IEC materials were created by that particular advertising agency. Now the NACO does not force us to use the advertising agency. We may create the materials ourselves and, in fact, we are strongly encouraged to do so.

K. Santosh : The IEC used for the study, as you said, was printed two years ago. But they are still being circulated by the government agencies to the NGOs to spread among the public. If the government has realized the inadequacy of these posters, it should have taken steps to remove them rapidly.

Usha Raghavan : I am not saying what has been done is right or wrong. I am just saying they were made two years ago. Again, the bureaucracy comes in. I do not want to talk about it. How it has been field-tested is a different issue. At that time we had a different set up.

To come to the recent IEC materials, we put in quotes “ field-testing ” them. As for the condom posters is concerned; every pack of condoms has a picture showing how to use them. Coming to the misinterpretation of communication, let us take the Shabana Azmi advertisement which appeared two years ago. Everyone, including NACO and IEC specialists, claim that people had the misconception that AIDS was connected only with children. Because Shabana Azmi had shown someone entering the paediatric ward and kissing an AIDS affected child. I won't say we, the representatives of the government, are absolutely on the right side. But we are not 100% on the wrong side, either. We definitely have to improve and IEC specialists with different skills must be appointed. But keep in mind that the centre (Delhi) does not put pressure on us. We have the option to choose the advertisement agency, we have to take upon us the whole responsibility.

Prof. Gurumurthy : What I wanted to say, was that anything prepared according to the guidelines given at the national level has to be adopted at the local level in our own way. My second point is that the social scientist is needed in selecting the informant. You cannot go and get an interview from a person who is unwilling.

G. Gunavathy : Of course, I could get about twenty five questions answered only from willing persons and not anyone who was either unwilling or about whom I had doubts regarding the way he made his statements. One factor I forgot to mention : on many of the posters, the woman has been portrayed as the vector of the disease and as being the dangerous half. There was a lot of objection from the woman interviewees.

Saraswathy Sankaran : Interestingly, when we asked pupils from secondary schools to draw something regarding AIDS one little chap wrote “ I hugged my mother and I got affection; I hugged my friend and I got friendship; I hugged my wife and I got pleasure. I hugged some unknown woman and I got AIDS ”.

S. Usha : The first sentence is all right, but you can hug a man friend and also get AIDS, being a woman yourself. It is again an illustration of how gender bias degrades women. Even if it is a poem written by a X standard student, it represents clearly how society perceives and accuses women.

Dr P.K. Das : Everyone has to restrict himself to his own field. A sociologist cannot be a communication specialist. So when you want to give a message to the target group, you have to describe the target group and ask the specialist to design accordingly. We have to congratulate the presenter, for she has pointed out the actual interpretation of the public for the first time. Otherwise everyone has been just putting up the posters everywhere without knowing the extent of their reach. Now we know the IEC material has to be changed.

Shyamala Ashok : The presenter should be congratulated, because for the first time, the limitation of the government, through IEC materials, have been pointed out. The worst fact is that other states are also using the same IEC as in TNSACS and only changing the language. Because the irony is that Tamil Nadu has been pinpointed has a model in terms of conceptualization and achievements with regards to AIDS prevention. But the funding agencies these days tell the NGOs not to prepare their own IEC material. They give out whatever they have in stock with them and do not provide funds for the NGOs to prepare their own IEC materials. Another sad thing is that the NGOs do not give grass root training to their people and also just grab whatever IEC they are given and place them everywhere as they do not have the money or persons to make them. It would have been better if the study had included these limitations also.

Saraswathy Sankaran : I would like to take the opportunity to introduce my organization, called DESH (Deepam Educational Society for Health). Our single objective is to spread social health education and in the current Indian scenario to fight AIDS. Being myself a sociologist, I am very particular to reinforce a practical approach through social science research to methodology, social action and evaluation. In the fight against AIDS, DESH utilizes cultural factors in contrast to biological factors. Research studies of people's lifestyles and level of living underline the sociological factors leading to a high-risk behaviour culminating in AIDS. Therefore, to contain AIDS, the need of the hour is a two way process, namely, from research to problem analysis to methodology implementation, then from methodology to action to

evaluation and back to the research to analyze more of the problem and work more effectively towards the solution. AIDS is not a problem which developed overnight. It is strongly rooted in the personality development of the individual. An indifferent lifestyle of high-risk behaviour, an ignorant mind not prepared to question, an accepting attitude based on laissez-faire, an outlook the society supporting absence/lack of empowerment : all these sociological factors and more are involved in shaping an increased vulnerability to the disease. Without understanding and tackling the root cause of AIDS, the disease cannot be tackled on a long-term basis. So far, DESH experiences have been in project implementation addressing vulnerable groups like youth, women, industrial employees and STD patients. We are presently working with school students in Chennai through a networking system between teachers, school children and administration. It is a dynamic and sustainable process in which professors are supposed to take our place when we withdraw.

Shyamala Ashok : At this juncture I should acknowledge Mrs. Saraswathy Sankaran. Earlier I was also her staff member and was working with her on this programme. How do you ensure that this programme is continued by the teachers ?.

Saraswathy Sankaran : Naturally I cannot be entirely sure. But I can say that to a certain extent at least 40% of them attended an exhibition which we hold. The teachers were able to tell us that they had brought out at present various issues regarding the epidemic. When a major donor of ours came to evaluate our work, we took him to a slum and three people passing through recognized our van. One recognized my staff member and one recognized me and said that after our programme in her school, which was a corporation school, she had taken it on her shoulders to go to the village and do some work there regarding HIV/AIDS.

Shyamala Ashok : The parents should be included in these programmes. The Parents Teachers Association (PTA) should be strengthened in these aspects. Most of the NGOs forget to use the parents in HIV/AIDS programmes. I think the sustainability would be improved if the parents were also included in the programmes.

Prof. Gurumurthy : When you are educating boys, what is the reaction of the parents to your imparting sex education or education on AIDS in the school ? Wherever parents and teachers associations could be involved, we have involved them. It is in the interest of their children that we are giving this education. So they have come forward. But we cannot do this in all the 404 schools. We have our funding limitations, but we work according to our conscience. We are now training the NGOs of Coimbatore and Periyar for the same purpose, and we are receiving requests from other NGOs and other schools. They too want such programmes in their schools.

Usha Raghavan : Regarding the scheme of Madras School of Social Work in the National Service Scheme (NSS), for students and headmasters, the same kind of programme is taken up by DESH (creating awareness among school children, etc.). They cover a lot of schools and they also do the follow-up. We are also funding them. With regard to what DESH is undertaking, there is a duplication of work that I want to be clarified.

Dr. Jeysingh : I shall describe the programme by NSS. This scheme is a programme of the government of India supported by the department of youth affairs and sports (two programmes : one for student youth and one for non-student youth). It provides assistance for organising AIDS awareness programmes throughout India. One million students are covered in Tamil Nadu and about fourteen thousand among ninety thousand students in colleges and fifty thousand in schools. The grant is given for two types of programmes, one for colleges and school teachers and another for students. At the first level, we give four days' training to the selected teachers who will be called NSS programme officers. NSS is not in all schools in Tamil Nadu. We have 1000 schools. With this scheme, we have about 9000 units in colleges. The teachers who are given training will go back to their schools and five students will be selected. They will become peer educators and educate the other students. When we train the school teachers, they say that the school headmasters and principals are the main obstacles. They do not permit the programme to be conducted. This drawback was already brought to the notice of the project director in Chennai, Mr. Bindhu Madhavan. Afterwards, he informed me to give the training programme throughout the state, mainly through headmasters. In that respect, it will give a long-term support to the programme. Therefore, we have chosen 1000 schools where the NSS has implemented the programme. The programmes in slums or communities are carried out in the same way. This is going to continue wherever NSS programmes are implemented. So, in order to give moral support to the programme, we think it is important to conduct the training programme via

headmasters. There is a hierarchy in India that we have to take into account, otherwise implementation will fail. Nevertheless, we find there are drop outs in the programme and we are taking up this matter at that stage. At Tirunelveli, TNSACS has funded a special programme for principals in colleges, as they were the bottleneck for the programmes. There was an issue as to the parents objecting to this kind of programmes being implemented in girls' schools in Trichy. As far as the NSS is concerned, it not only creates awareness programmes. Rallies and competitions are also conducted, particularly on world AIDS Day. Even the NGOs might be aware of this as there is, in fact, a collaboration between the local NGOs and the NSS training programme officers. When we arrange such meetings, we have feedback from the community. At that time, there is another issue as to why the training programmes are only for 12th class pupils and not the younger ones. But to come back to the initial question raised by Usha Raghavan, there is no duplication with the DESH project.

Dr P.K. Das : I strongly disagree with the rally programmes which are fashionable nowadays in India. That is only an excuse for not taking the programmes to the classes. There is no impact in the sense that it is just an individual event which is not rooted in the life of the students. It may be like going to the cinema or any other amusement for them. We should take care of the quality of education and not just make a programme with no impact. I may be exaggerating a little, but try to evaluate the feedback of such a rally after one week or one month.

HIV/AIDs prevention programmes: streamlining intervention and evaluation strategies

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This paper is about HIV/AIDS prevention programmes and the part played by evaluation. Basically, it is about streamlining intervention and evaluation strategies. We evaluated a project by the government of Maharashtra, in 1995. In the same way, an evaluation was done in Tamil Nadu MSSW. In rural Maharashtra in all schools, the intervention programme was carried out by the government and funded by UNICEF and our Institute. The International Institute of Population Science was given the task of evaluation. As usual, we did the pre- and post- test and the results were different. I do not want to discuss that, but plan to discuss the problems that we faced during the evaluation and what we can suggest for the intervention and evaluation programmes. This is not an exhaustive list; I am just mentioning the problems we faced during the evaluation. I will first discuss the evaluation issue. Basically, we think that, as an evaluator, we should be clearly told about the objectives of the evaluation. This is lacking in many of the intervention programmes. For example, whether feedback is needed on process, context, outcome or impact. When objectives are unclear, the evaluation agencies like us have a difficult time in finding out what research tools are to be used.

Introduction

In a country like India, where the majority of the population lives in rural areas and below the poverty line, is largely illiterate and is characterized by high fertility and mortality rates, intervention by the government and voluntary agencies is a necessity. This is particularly the case in the field of health services and education. In recognition of this need, various health intervention programmes have been implemented and, with the advent and spread of HIV/AIDS, and because of the non-availability of curative measures, it has become imperative to intensify intervention efforts aimed at educating the population as to the seriousness of the problem and the ways to remain free from the dreaded disease. Periodic efforts are also necessary to assess or evaluate the effectiveness of the intervention programmes so that necessary modifications or improvements can be made before they are replicated elsewhere. Nevertheless, in their eagerness to implement the intervention programmes as quickly as possible, planners and administrators think of the evaluation component only later and not at the introductory stage. Largely because of this, programme evaluation becomes monotonous, and is carried out in a mechanical manner, often without the use of appropriate research tools. The possibility of this happening is all the more when the same agency is responsible for both the intervention and the evaluation.

The International Institute of Population Sciences has in the past conducted evaluation studies both for the government and for donor agencies. One such study was the evaluation of the AIDS intervention programme carried out by the Government of Maharashtra, in 1995, on behalf of UNICEF. Based on our experience (Verma et al, 1995) and the extant literature (Vimala Nadakami et al., 1994; Janz K. Nancym et al., 1996; Scrimshaw Susan C. et al., 1991; Bawaikar Ruma and Vidya Pillai, 1996; Forrest Jacqueline D. and Jane Silverman, 1989), what follows is a discussion of how an intervention programme regarding HIV/AIDS can be best designed and implemented, along with suggestions about the methods to be used for effective evaluation. Highlighting the general objectives of HIV/AIDS prevention programmes, in the first section, the paper discusses the broad strategies adopted in these interventions. It then discusses the need for evaluating the AIDS prevention intervention programmes and problems therein. The paper finally suggests a few evaluation strategies.

HIV/AIDS interventions: objectives and strategies

The pattern of HIV/AIDS spread in recent years has highlighted the importance of interventions focusing not on sex workers or those identified as risk groups such as truck drivers and single male migrants, but on people, and more specifically on women, in the general population (Verma et al., 1997). For example in Maharashtra, which has reported the highest number of AIDS cases in the country, the official data suggest that the HIV spread is on the rise. The Elisa (test) reactivity rate for the year 1997 was 2.5 per cent and the HIV prevalence amongst high-risk groups rose from the 9.7 (1988) to 11.04 per cent (1996). The HIV prevalence has also steadily increased in sentinel groups like antenatal mothers (Salunke, 1997). Recent evidence suggests the increase of HIV among women who report having monogamous relationships. The most common route of HIV transmission being heterosexual, an intervention based on the clear understanding of sexual behaviour in different age and social groups becomes inevitable. The most vulnerable group seems to be youth, and particularly women, in the general population, between the ages of 20 to 40 years, and a need for a community-based approach to inculcate

family life education has been recognized. At the same time, growing evidence has suggested that the presence of STDs increases the transmission efficiency of HIV.

Objectives of most intervention programmes

1. To increase the level of information about STD/HIV/AIDS ;
2. To increase the knowledge about safer sex ;
3. To increase the utilization of condoms ;
4. To heighten consciousness regarding health ;
5. To provide STD/HIV/AIDS prevention and support services, such as STD treatment facilities.

Involvement of the community

While working with groups like sex workers and others with multiple partners, it becomes necessary to concentrate on changing the individual risk behaviour. On the other hand, when working with women in the general population, it becomes necessary to aim at the mobilization of the community to take action for the prevention of the spread of the AIDS pandemic. This strategy has to be adopted because the immediate danger to the target population is not obvious. HIV prevention is one of the services provided under the broad umbrella of reproductive health services which, in addition, include services for contraceptive, maternal and child health, safe abortion, infertility, reproductive tract infection and sexual health. It is worth noting that the Government of India is now committed to adopting this approach to the population control programme. It is, therefore, expected that once this approach is adopted and implemented, HIV/AIDS prevention would be a regular feature of the health care system of the country.

NGOs also occasionally take the lead in setting up AIDS intervention programmes, taking into account the social needs of a specific area. Some interventions do not make any direct reference to women's empowerment, but are mainly concerned with creating widespread awareness about HIV/AIDS and STDs. Hoarding, posters, newspaper advertisements, radio and television spots, bear testimony to this approach. SEWA Rural, while aware that there is a great deal of high-risk behaviour in the tribal community in which this organization works, does not feel confident at the stage of a strategy that would target persons in the community who have the highest risk of getting infected or who would transmit the infection, with the intention of modifying their sexual behaviour. Creating general awareness is, therefore, considered a necessary and useful start. In such a situation, in addition to community-level action, the importance of the potential of the available health care system for identifying and treating STD cases needs to be recognized. Training of health personnel and strengthening of referral support systems have, therefore, been taken up on a priority basis. A special programme for increasing awareness of newly married couples about their own health, including reproductive health, has been undertaken. Education of this group in sexuality is considered crucial for creating a critical mass of informed and motivated individuals in the age group at high risk of contracting STD/HIV/AIDS. Such a strategy is considered to hold great promise for providing a solid base for any HIV/AIDS intervention programme (Jaya Shreedhar and V. Colaco, 1996).

Adolescence is a period of rapid physical and psychological changes. During this transitional stage between childhood and adulthood, the foundation for the development of positive attitudes and healthy lifestyles can be laid. Of particular relevance to the HIV/AIDS epidemic is the widespread ignorance about human sexuality among adolescents in India. The paucity of reliable sources of correct information and inaccessibility of the few that are available make it imperative for government and non-governmental organizations to take up large-scale programmes covering this sensitive topic. Such efforts are further justified when it is realized that HIV transmission occurs in India through sexual contact. For even in the Northeast, particularly Manipur where intravenous drug injections are a major mode of transmission, unsafe sexual contacts are widely recognized to be a cause adding to the complexity of the problem. Adolescents are prone to experimentation and therefore need to be equipped with correct knowledge about HIV/AIDS so that they can guard themselves against all STDs, including HIV/AIDS. Early intervention during adolescence could be an effective way to safeguard their future health. Adolescent Indian girls, like adult Indian women, are at a particular disadvantage with regard to knowledge about their own sexuality and related problems, because they are trapped in the culture of silence inhibiting any verbalization of their problems, physical or otherwise. Interventions for adolescents could be classified according to the setting in which these are carried out. The interventions are either community-based or educational institution based.

Community-based interventions

Community based interventions are essentially characterized by two approaches: while some have attempted educational intervention among women in the community, others have attempted the networking of services in the community (educational-cum-services). While such interventions require efforts to build up community support and involvement, interventions carried out in institutions, especially educational institutions, need the conviction and support of the policy- and decision-makers at the top level; while at the lower level, the management skills of the administrators are required to work out the logistics of carrying out the various intervention activities. One advantage of the institute-based strategy is that a captive audience, in this case the students, is readily available for the intervention. In most HIV/AIDS intervention programmes, the need is not felt by the target population, but by people standing outside the explosive situation.

It does not appear that different strategies are employed for different approaches. It is also not realistic to expect an approach-specific strategy. Efforts to operationalize the approach are generally concerned with involving the community in different ways to become partners in the intervention programmes. Yet another strategy is to equip the health care system in order to be ready to face the problems arising out of the impending epidemic. This strategy of course works in conjunction with a programme for spreading awareness about HIV/AIDS/STDs in the general population and providing them services, sometimes with special attention paid to the more vulnerable groups such as women.

Evaluation issues

Clear objectives

Generally, the evaluation agencies are not told what is expected of them in the process of evaluation: for example, whether feedback is needed on process, context, outcome or impact. In case of unclear objectives, it is left to the evaluating agency to think of the tools for evaluation without understanding why an evaluation is required at that particular stage of a programme. An examination of the various evaluation studies of AIDS intervention programmes reveals that these have been carried out at the end of the intervention programmes. This means that the implementing agency is only interested in using the evaluation as a tool to measure success, rather than using the findings to learn about shortcomings and later improve strategies by incorporating the suggestions. Therefore, it is very necessary to have mid-term evaluations of HIV/AIDS intervention programmes so that the shortcomings, if any, can be rectified and used as a model for future programmes.

Assumptions involved in the intervention

Before evaluating any programme, it is necessary for evaluating agencies to understand the underlying assumptions involved in the intervention programmes. However, our experiences tell us that the assumptions involved in the programme are usually not critically examined in the evaluation to understand the process of change in the attitude or behaviour of the masses. For instance, in the AIDS intervention programme at the school level, the underlying assumption is that the attitude of the students towards HIV/AIDS patients could be improved by better knowledge and also as a result of the involvement of teachers and parents in the programme. But what usually happens is that the efforts of teachers and parents are neglected and hence the evaluation remains to a greater extent partial. Similarly, intervention programmes to promote the use of condoms merely target commercial sex workers because it is felt that use of condoms as a barrier method could be increased through these women. However, the attitudes of the clients should be taken into consideration; but, this is never done. Thus, for any meaningful evaluation, it is essential to clearly understand the assumptions involved in the programme.

Specific indicators

None of the evaluation studies have so far attributed changes occurring between pre- and post-intervention studies completely to the intervention programmes. This clearly shows that, more than the success of any intervention programme as such, importance should be given to the specific indicators, such as how far the target groups have started discussing HIV/AIDS with their peers; whether they are more comfortable discussing the issues of HIV/AIDS with their parents, etc. This is just to say that studying the inception of the change in the process is much more worthwhile than confining the evaluation to the end results of the post-intervention studies.

Participatory evaluation

The evaluating agency should be involved in the intervention programmes so that it is aware of the strategies tried out in disseminating the message to the masses. Participatory evaluation here is a situation where the evaluating personnel are present during the process, but only as observers. This would also help them think of all suitable techniques to be used in measuring the impact of intervention. Further, as an important component of participatory evaluation, there should be discussions with the target groups to understand the different components of intervention that have to be evaluated in order to strengthen both intervention and evaluation strategies. For instance, it should be determined whether the medical components of HIV/AIDS transmission are discussed in the intervention programme before framing questions on Syphilis B.

Hidden agenda

Generally, it is found that the evaluating agency is reluctant to be critical of the intervention and consequently most of the evaluation studies conclude that the intervention has been very successful, even when the impact has only been marginal. This is because the intervening agency is also the source of funding for the evaluation, and saying that an intervention programme has not been successful would not be the proper thing to do. Further, the hidden agenda in many of the evaluation studies is to be in the good books of the funding and implementing agencies by reporting a programme as a successful one, so that the relationship continues and they get many more projects to be evaluated. This hidden agenda definitely needs to be addressed seriously since it affects the ethic of research and, to a greatest extent, the beneficiaries of the programme. The point to be noted is that the intervening agency should not be involved in the selection of the evaluating agency.

Specific target group

It is the duty of the programme officials to clearly distinguish between the primary and secondary targets of the AIDS intervention programmes. For instance, in an intervention programme at the school level, the primary targets would be the students and the secondary target would be the teachers. But, in most such programmes the evaluation is focused on the students, and teachers (the secondary targets) are not at all considered, or are given least importance. This happens only if the programme officials do not specify their target groups, as a result of which the evaluation agencies miss out on the other modes of dispersion of messages.

Combine both qualitative and quantitative methods of evaluation

Most of the intervention programmes are evaluated with the help of a structured questionnaire which limits the options available to the respondents to express their views. This to an extent depends on individual guesswork and hence should not be strictly taken as an indicator of change in the process. It would be appropriate to use qualitative techniques such as focus group discussions and in-depth interviews to understand the exact change in the awareness and attitude towards various issues of HIV/AIDS. While analyzing the evaluation results, many agencies tend to opt for a variable, 'average score', which is nothing but an average of the number of HIV/AIDS issues to which the target group gives correct answers. For instance, while this average gives only the overall picture, knowledge of and attitude towards specific issues like the use of condoms, or commercial sex workers as carriers of HIV, are not given due weight. Hence, it is important that in addition to the 'average score', the different issues related to HIV/AIDS should also be addressed.

Issues which require attention in the intervention programme

Design

For any intervention programme to be successful, it should be so designed that the following points relating to population characteristics are given due consideration: the geographical area, population size, age, level of education, place of residence and occupation should be taken into account.

Size of the target group

The target groups in the intervention programmes should be small enough so that the message reaches them in the right way. To be specific, it would be difficult for the evaluating agency to contact the same target group before and after the interventions. Generally, it is observed that if the target group is large, there is always a chance of also interviewing persons who were not covered by the intervention programme. This definitely would alter the post-intervention results.

Who should be involved in the intervention programme

The intervention programmes of the government with the aim of creating awareness about HIV/AIDS are carried out by the health officials of the district in colleges and schools with the help the teachers. This may not evoke adequate interest from the students attending the intervention programmes, as they view it more as another routine lecture than as one which could be life saving. In order to create interest in the subject, peer groups of students could be trained in the first stage and then later asked to discuss the problem with their friends and spread the message. This would also increase the interaction between the trainers and the students, which is generally missing from many of the intervention programmes.

Duration of the intervention programme

The duration of an intervention programme is also important in achieving an overall impact on the masses. For instance, if the duration is too short, then there is a danger of overburdening (covering too many issues in too short a time) the target group with all the issues of HIV/AIDS, perhaps generating confusion. On the other hand, if the duration is too long, then there is a problem of students dropping out, which might affect the overall objective of the programme in disseminating the message. Therefore, the duration of the intervention programme should be kept in mind before starting the programme.

Interval between pre- and post-intervention surveys

Usually, the time gap between the intervention programmes and the evaluation is too short to appraise the influence of the intervention. This is comparable to teaching students in class one day and asking them to appear the very next day for the exam. Since the evaluating agency is only interested in affirming that there is a definite change in the awareness of the students compared to the pre-intervention periods, the issue of time interval is generally neglected. Similarly, the mass literacy programme is criticized to a great extent because the effects were assessed immediately after the literacy promotion drive and it was found there was 100 per cent literacy in many villages. However, another assessment after a few years clearly reveals that a majority reverted to being illiterate as they could not absorb and retain the knowledge imparted. So the long-term effect of message retention is more important than the immediate effect. Therefore, it is very important to spread the message continuously rather than giving the message for a very short duration and expecting a phenomenal change in the years to come.

Briefly stated, this paper cautions the introduction of HIV/AIDS intervention programmes in any society with the associated problems, considers the difficulties involved in evaluating these programmes and the ways to deal with the same.

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Discussion

Prof. Gurumurthy : It would be better to clarify the difference between a consultant and an evaluator. If the evaluator plays the role of a consultant he operates on at least two different levels (giving advice, judging). But the evaluator comes at the end to determine the effect of the programme, or what is wrong or right in the methodology or the techniques adopted in the programme. If you start playing two roles don't you think we will have some problems ?

S. Surender : I behave as an observer more than an evaluator and consultant. I should know what is going on in the programme in order to evaluate it in a better way. I am not going to suggest anything for the intervention programme as such. I am just an observer of the intervention programme. I am just an observer to understand what materials are supplied, what is going on in the programme intervention, what workshops are conducted, what are the areas about which people are talking. On this only, I can frame questions or study to evaluate a particular aspect of the project.

Prof. Gurumurthy : The role of a consultant is to give advice to the project operator.

Dr P.K. Das : S. Surender has brought up an important point: if the evaluator does not know what the programme is about, then he cannot evaluate the programme. Because he is not taking the role of consultant who is proposing a certain strategy. The purpose of programme evaluation is to provide a final evaluation and a process evaluation. We are not only interested in success or failure, we are also interested in knowing what process leads to success or failure. Therefore, it is important for the evaluator to be as a silent observer at every step of this involvement. He must know what the objectives are, what processes are going to be implemented. Your techniques may be perfect, but you may go wrong, or you might have gone wrong in the stage of implementation. The evaluator is part of an overall system in which he has no influence on the strategy as such. But he should know what is behind the strategy, how it is implemented and what processes are involved. Therefore, a consultant and an evaluator are two entirely different things. The government insists that every programme should have an inbuilt evaluation report.

Prof. Gurumurthy : Before the government renews its grants or accepts a report, it needs an evaluation report of the programme by an expert. Because a government agency or a funding agency would not have the technical know-how, it is a pre-requisite that an evaluation report should be included. But I fail to understand what " inbuilt report " means.

Dr P.K. Das : There is a group which is appointed to look into this type of programme. For example, the Vector Control Research Centre is looking into the National programme in which we participate, but we cannot influence what they should do. We just see what their strategy is all about. We should understand where they want to go; then only we can find out whether they have gone there or not, and by what means they have been able to get there. These are two different things.

Prof. Gurumurthy : But you have to tell them where they have gone wrong and how. Why only in the end ? Therefore, what is the purpose in keeping a watch on them continuously ? Because telling them at the end where they have gone wrong is not useful. You said yourself that prevention is better than cure.

S. Sureender : That is why I said a mid-term evaluation is needed and we are suggesting some strategies for the implementation and intervention. We suggest these strategies whenever someone asks about the evaluation we have done. We need to know thoroughly about the intervention programme, how it proceeded, whether it has actually been done in schools. We have only to observe. Then we can have a proper evaluation.

Dr P.K. Das : After evaluation, we tell the programme operators that we give them the choice of how they could have done the programme. We cannot force them and we do not interfere at every step. Because if we interfere at every step, the person who is implementing the programme can always say that only because of the interference he could not do this or that. At the same time, we cannot allow mistakes to repeated year after year. So these are very clear guidelines. And the evaluation science is very well developed and there is no scope for any doubt that the evaluation process influences it or not. Many evaluation programmes are mostly window dressing, like when the government conducts the evaluation programmes. They only show the positive aspect, but not the negative aspect. When an evaluator is doing the evaluation, he is unbiased; he has nothing to hide.

F. Bourdier : The debate may be interesting, but it is digressing. It is expected that we give some practical suggestions or illustrations regarding our experiences, not only in an abstract way. Does anyone wish to intervene with facts which would illustrate the Das, Gurumurthy and Sureender discussion ?

Dr Shukla : I will speak about mine. Whenever my project applies for funding, it has to show its objectives, either long-term or short-term. Whenever there was an evaluation, the project has to be evaluated according to short-term or long-term objectives. But if there are no clear-cut objectives in the report itself, that missing point should be sufficient for the evaluator to decide what to evaluate in terms of your objectives. Another point is that when we submit a project, there should be an evaluation every two months by our own group of evaluators and every six months by an outside group. If that is not included, then the project is not sanctioned. At the end of the project we ask the outside evaluators to submit their reaction, but it is not sufficient : every two months they should carry out their own evaluation. We need this because we are not specialists. We are promoting collaboration between people in action and people in research, but this should be built in the project itself.

F. Bourdier : We have to come to reality in terms of material constraints, whether the money spent on the project is taken for evaluation or not. But is it possible to make evaluations every one or two months ? How do you proceed practically ?

Dr Shukla : There is an internal evaluation when a project is given by an NGO. They have about eight to ten people actively involved in the work. They have to sit every one or two months and evaluate where they have gone wrong or whether they have identified an improvement or a necessity to adjust a particular point.

Dr P.K. Das : What is a plan ? It is a list of activities which a particular organization is going to carry out. And when these activities are decided, the organization puts them in a time-frame. Once, I was talking with one of my colleagues about the activity of that year and he said that he was supposed to have carried out certain activities by that time. But he could not do so because of various constraints. That is part of the internal evaluation where you are monitoring your own activities.

Prof. Gurumurthy : There are three persons involved. When a project proposal is submitted, it is sent to some expert to ascertain its viability respective of funding, time, resources and the other aspects. The report is then evaluated by the expert and sent to the funding agency. Then it is to be sanctioned. The second phase is the self- evaluation, whether one is going in the right direction at the right pace and in the right manner. The last evaluation concerns the work already done, what was supposed to have been done, what has been done and what is to be done. You need to have three types of evaluation, as there are three stages.

John Dalton : Generally NGOs are not very clear about the evaluation. In most cases one writes the proposal, and another has some vision. Then they face certain problems, like instability of staff, instability of funding and so on. Very often, as I have noticed, many of the staff within the project are not self-evaluative. They feel that it is actually the job for the evaluator to come and make the evaluation. But actually, it is the job of everybody to evaluate. When I go to work, I should evaluate what I should do. It is not monitoring. When we monitor the activities, one should be self-evaluating, self-monitoring. But very often, this is not done. We generally have vague ideas about evaluators. When someone comes to evaluate, he sometimes asks that staff to evaluate the programme, instead of doing and going away. It helps on the long-term as well.

Saraswathy Sankaran : The evaluator comes at the end of the year or the term of the project. But at the end of one year, if we had waited for just the external evaluation, I don't think we would have reached where we have reached the point we have today. The continual internal evaluation goes a long way. The programme officers would go and evaluate. We have brought out twelve different questionnaires, because we cannot rely on one questionnaire. We are unable to evaluate just at one go, or say five goes, so we continue to change the questionnaire and now we have brought out the twelve questionnaires and we feel that this one would solve many of our problems. This is internal evaluation. Too much external evaluation can be a disturbance in the sense that a project is not something going on in a linear way.

Effectiveness of audiovisual media as compared to the conventional lecture method in the prevention and control of the AIDS epidemic

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The HIV infection has become quite common throughout the world, but patterns of occurrence and cause vary from one part of the world to another. The first case of infection was detected in India in March 1986. The virus spread with great rapidity throughout India, along the western and eastern coasts and inward to all parts of the country. The spread of HIV varies from one region to the other reflecting the nature of the country's diversity. Most of the HIV infections go unrecognized and unreported due to the lack of HIV testing facilities.

It was estimated that 1.75 million people in India would have been infected with HIV by the end of 1994. According to a statement of the National AIDS Control Organization, up to one million people in India will be infected with HIV and two million are likely to develop AIDS by the year 2000. HIV is rapidly spreading among the general population, mostly by means of sex between people who do not realize that they may be passing on or receiving the virus during unprotected sexual intercourse.

As there is no cure for the HIV infection, we can prevent the general public from being infected only through education. Educational technology has the potential to create a climate for development through behavioural modification in the public for effective communication and responsible decision-making behaviour that may protect them from the HIV infection. Hence, there is a need for a study like the present one to determine whether educational technology would promote behaviour that can prevent the transmission of HIV among the general public.

Objectives of the study

The objectives of the study are stated as follows:

1. to find out whether the conventional lecture method and different instructional media, namely audio and video, are effective in bringing about behavioural change among undergraduate students in the context of the prevention and control of the AIDS epidemic;
2. to find out the relative effectiveness between the conventional lecture method and different instructional media in bringing about behavioural change among undergraduate students in the context of the prevention and control of the AIDS epidemic;
3. to find out whether there is any significant difference between the conventional lecture method and different instructional media, namely audio and video, as regards their effectiveness in enhancing the retention of the modified behaviour among undergraduates in the context of the prevention and control of the AIDS epidemic.

Hypotheses of the study

The hypotheses of the study are stated as follows:

There is a significant difference between the means of pre- and post-test scores of the subjects belonging to groups receiving the lecture method, or those where different

instructional media were employed, namely audio and video, with regard to awareness of the AIDS epidemic.

There is a significant difference between the lecture method and the different instructional media, namely audio and video, in their effectiveness in bringing about behavioural change with regard to awareness and attitude towards the AIDS epidemic.

There is a significant difference between the lecture method and the different instructional media, namely audio and video, in their effectiveness in terms of retention of changed behaviour in awareness and attitude towards the AIDS epidemic.

Tools used in the study

The following tools were used in the study:

1. The achievement test in AIDS awareness developed by the investigators. The test items were selected within the scope of the contents of the audio and video materials employed as experimental intervention.
2. An attitude scale developed by the investigators. The statements reveal both positive and negative attitudes towards the AIDS epidemic. The scale consists of 35 statements.

Methodology of the study

The pre-test, post-test non-equivalent groups design was found to be the most appropriate experimental design to test the formulated hypotheses. Three groups of undergraduate students, thirty in each group, studying in three different arts and science colleges in the city of Coimbatore were formed. The homogeneity among the groups was established with respect to AIDS awareness and attitude towards the AIDS epidemic as measured by the pre-test. One of three groups was treated as the control group, while the other two groups were treated as experimental groups. The conventional lecture method was adopted in the control group, while audio and video programmes as experimental methods were employed in the experimental groups. Post-tests in AIDS awareness, as well as regarding attitude towards the AIDS epidemic, were administered to all three groups one month after the experimentation had been concluded.

The responses made by the subjects of the control and experimental groups to all three tests were scored, tabulated and analyzed using appropriate statistical techniques.

Analysis and interpretation of data

The mean and S.D. of the scores of the students of the control and experimental groups on AIDS awareness and attitude towards the AIDS epidemic as measured by the pre-, post- and retention tests were computed.

In order to test Hypothesis 1, "t" tests were attempted between the means of the pre- and post-test scores on AIDS awareness of all three groups. The results are given in Table 1.

TABLE 1

SIGNIFICANCE OF DIFFERENCE BETWEEN THE MEANS OF PRE- AND POST-TEST SCORES ON AIDS AWARENESS FOR CONTROL AND EXPERIMENTAL GROUPS

S. NBo Group	Pre-test		Post-test		D	D	t
	Mean	S.D.	Mean	S.D.			
1. Control 15.28* Group	27.8	4.01	43.2	3.7	15.4		1.01
2. Experimental Group I	25.6	4.11	43.06	3.0	17.46	0.93	18.77*
3. Experimental	26.5	4.15	40.15	3.51	13.65	0.99	13.79*

* Significant at 0.01 level
Degrees of Freedom : 58.

From Table 1, it is found that there is a significant difference at 0.01 level between the means of pre- and post-test scores on AIDS awareness. The mean value of the post-test scores is found to be greater than that of the pre-test for all three groups. Hence, it is concluded that the lecture method and the audio and video programmes are effective in bringing about changes in the intellectual behaviour of the undergraduates with regard to the AIDS epidemic.

In order to test Hypothesis 2, "t" tests were attempted between the means of pre- and post-test scores of the subjects of control and experimental groups on attitude towards the AIDS epidemic. The results are given in Table 2.

TABLE 2

SIGNIFICANCE OF DIFFERENCE BETWEEN THE MEANS OF PRE- AND POST-TEST SCORES ON ATTITUDE TOWARDS THE AIDS EPIDEMIC FOR THE CONTROL AND EXPERIMENTAL GROUPS.

S.No Group test	Pre-test		Post-		D	D	t
	Mean	S.D.	Mean	S.D.			
1. Control Group	123.90	15.31	136.22	9.85	12.32	3.32	3.71*

2. Experimental	117.67	9.97	122.67	15.98	5.0	3.44	1.45	NS
3. Experimental	120.62	10.54	125.65	9.54	5.03	2.60	1.94	NS

 * Significant at 0.01 level

NS not significant

N1=N2=N3=30

Degrees of freedom = 58

From Table 2, it is found that there is a significant difference at 0.01 level between the means of pre- and post- test scores in the case of the control group, while there is no such difference between pre- and post-test scores in the case of the experimental groups. It is also seen that the mean value of the post-test scores is greater than that of the pre- test scores. Hence, it is concluded that the conventional lecture method is quite effective in bringing about attitudinal change with regard to the AIDS epidemic.

To test Hypothesis 3, "t" tests were attempted between the means of the scores of the control and experimental groups on AIDS awareness and attitude towards the AIDS epidemic as measured by the post-test. The results are given in Table 3.

TABLE 3

SIGNIFICANCE OF DIFFERENCE BETWEEN THE MEANS OF CONTROL AND EXPERIMENTAL GROUPS ON THE SCORES OF AIDS AWARENESS AND ATTITUDE TOWARDS THE AIDS EPIDEMIC AS MEASURED BY THE POST-TEST.

.S.No Groups compared	M1	SD1	M2	SD2	D	D	t
AIDS Awareness							
1. CG Vs EG I	43.20	3.78	43.06	3.0	0.14	0.88	016NS
2. CG Vs EG II	43.20	3.78	40.15	3.51	0.94	0.94	3.25*
3. EGI Vs EG II	43.60°	3.00	40.15	3.51	2.91	0.84	1.0 NS
ATTITUDE TOWARDS THE AIDS EPIDEMIC							
4. CG Vs EG I	136.22	9.85	122.67	15.98	13.55	3.43	3.95*
5. CG Vs EG II	136.22	9.85	125.65		9.54	10.54	2.50 4.22*
6. EGI Vs EG II	122.67	15.98	125.65		9.54	2.98	3.40 0.88NS

* Significant at 0.01 level

NS Not significant DF=58

N1=N2=N3=30

From Table 3, it is found that there is a significant difference at 0.01 level between the means of the control group and experimental group II on the scores of AIDS awareness and attitude towards the AIDS epidemic. The mean values of the control group are found to be greater than that of experimental group II. Hence, it is concluded that the conventional lecture method is more effective when compared to video media in bringing about change in cognition and attitude in the context of the prevention and control of the AIDS epidemic.

It is also found that there is a significant difference at 0.01 level between the means of control group and experimental group I in the scores of attitude towards the AIDS

epidemic. The mean value of the control group is found to be greater than that of experimental group I. Hence, it is concluded that the conventional lecture method is more effective when compared to the audio medium in bringing about attitudinal change in the context of the prevention and control of the AIDS epidemic.

It is also found that there is no significant difference between the means of experimental groups I and II in the scores of AIDS awareness, as well as attitude towards the AIDS epidemic. Hence, it is concluded that audio and video media are equally effective in bringing about the desired changes, both cognitive and affective, in the context of the prevention and control of the AIDS epidemic.

Again, it is found that there is no significant difference between the means of the control group and experimental group I in the scores on AIDS awareness. Hence, it is concluded that the conventional lecture method and the audio medium are equally effective in bringing about cognitive change in the context of the prevention and control of the AIDS epidemic.

In order to test Hypothesis 4, "t" tests were attempted between the means of the control and experimental groups in the scores on AIDS awareness and attitude towards the AIDS epidemic as measured by the retention test. The results are given in Table 4.

TABLE 4

SIGNIFICANCE OF DIFFERENCE BETWEEN THE MEANS OF THE CONTROL AND EXPERIMENTAL GROUPS IN THE SCORES ON AIDS AWARENESS AND ATTITUDE TOWARDS THE AIDS EPIDEMIC AS MEASURED BY THE RETENTION TEST.

S.No	Groups Compared			M1	SD1	M2	SD2	D	D	t

AIDS AWARENESS										
1	CG	Vs	EG1	36.6	3.76	38.83	3.21	2.23	0.90	2.48 §
2;	CG	Vs	EG2	36.6	3.76	34.42	3.62	2.18	0.95	2.29 §
3	EG1	Vs	EG2	38.83	3.21	34.42	3.62	4.41	0.88	4.99 §
ATTITUDE TOWARDS THE AIDS EPIDEMIC										
CG	Vs	EG1	128,8	8,16	121,6	15,62		7,2	3,22	2,24§
CG	Vs	EG2	128.8	8.16	122.42	11.12		6.38	2.52	2.53 §
EG1	Vs	EG2	121.6	15.62	122.42	11.12		0.82	3.50	0.23NS

* Significant at 0.01 level

§ Significant at 0.05 level

NS Not significant

N1=N2=N3=3.0 DF=58

From Table 4, it is found that there is a significant difference at 0.05 level between the means of the control group and experimental groups I and II in the scores on AIDS awareness and attitude towards the AIDS epidemic as measured by the retention test. The mean values of experimental group I is found to be greater than that of experimental group II in the case of attitude towards the AIDS epidemic. Hence, it is concluded that the conventional lecture method is more effective when compared to audio and video media in enhancing the retention of attitudinal change in the context of the prevention and control of the AIDS epidemic.

It is also found that there is a significant difference at 0.05 level between the mean of the control group and experimental groups I and II. The mean value of the control group is found to be greater than that of experimental group II, while the mean value of experimental group II is found to be greater than that the control group in the scores on AIDS awareness as measured by the retention test. Hence, it is concluded that the conventional lecture method is more effective when compared to the video medium, while the audio medium is more effective when compared to the conventional lecture method in enhancing the retention of changed behaviours in cognition in the context of the prevention and control of the AIDS epidemic.

Again, it is found that there is a significant difference at 0.01 level between the means of experimental groups I and II in the case of AIDS awareness scores, while there is no such difference between there is different groups regarding the attitude towards the AIDS epidemic as measured by the retention test. The mean value of experimental group I is found to be greater than that of the video medium with regard to AIDS awareness scores. Hence, it is concluded that the audio medium is more effective when compared to the video medium in enhancing the retention of attitudinal change in the context of the prevention and control of the AIDS epidemic.

Recommendations

On the basis of the findings of the study, the following recommendations are made:

1. The conventional lecture method and audio and video programmes are all effective in bringing about the desired behavioural changes among undergraduate students in the prevention and control of the AIDS epidemic. Hence, all three instructional methods can be readily employed in AIDS awareness programmes.

2. Centralized support units for AIDS awareness programmes may be established in every district for the production and distribution of media materials on AIDS education.

3. Media materials on AIDS awareness may be promoted in order to educate men and women to assume their responsibilities in relation to the HIV/AIDS epidemic.

4. Action-oriented reflection programmes on the HIV/AIDS epidemic using media materials may be undertaken in order to empower women to protect themselves from infection.

5. Educational audio and video programmes may be promoted in order to provide quality care for HIV/AIDS-infected individuals and mobilize support for them in the general public.

Influence of linguistic and cultural background of the media materials on media effectiveness in prevention and control of the AIDS epidemic

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The HIV infection becomes a problem with social, cultural, economic, political, ethical and legal implications. Sexual behaviour being the predominant mode of transmission of HIV, steps should be taken to educate the high-risk groups of people in order to prevent and control HIV transmission. People of the age group 16 to 24 are a potential target population for the prevention of the HIV infection. It is found that at least one-fifth of all AIDS patients are in their twenties. As there is no cure for HIV infection, we can only prevent this vulnerable group from being infected through education.

Information, values and skills conveyed through programmes for the prevention and control of the AIDS epidemic may have a considerable impact on the lives of young people, so that they can maintain healthy behaviour, besides preventing fear and discrimination. It is imperative to establish through education that HIV-infected people are free to participate fully in the learning environment.

Problematic

The HIV/AIDS preventive action must be specific to the target population and bring knowledge, skills and attitudes together in a coherent whole. It should also be sensitive to the needs and characteristics of the educators and learners. The educators may also choose the most appropriate teaching styles and strategies for imparting knowledge and inculcating the right attitude towards the prevention and control of the AIDS epidemic. Instructional media, viz. audio, video, slides, posters, etc., are effective in realising the instructional objectives and may also be exploited in the prevention and control of HIV infection. The value of an instructional medium is supposed to lie in its adaptability to the local, social and cultural environments. Hence, this study aims at finding out whether the linguistic and cultural background of medical materials has any influence in determining their effectiveness in the prevention and control of the HIV infection.

The objectives of the study are stated as follows

1. To find out whether the linguistic and cultural background of the video programmes on the prevention and control of the AIDS epidemic influences their effectiveness in terms of knowledge gain among undergraduate students.
2. To find out whether the linguistic and cultural background of the video programmes on prevention and control of the AIDS epidemic influences their effectiveness in terms of attitudinal development among undergraduate students.

The hypotheses of the study are stated as follows

1. The linguistic and cultural background of the video programmes on the prevention and control of the AIDS epidemic influences media effectiveness in terms of knowledge gain among undergraduate students.

2. The linguistic and cultural background of the video programmes on the prevention and control of the AIDS epidemic influences media effectiveness in terms of attitudinal development among undergraduate students.

Tools used

The following tools were used in the study to collect the required data:

1. Achievement test in AIDS awareness
2. Attitude scale towards AIDS

Methodology

The pre-test post-test non-equivalent groups design was found to be an appropriate experimental design to test the formulated hypotheses of the study. Sixty undergraduate students studying in the first year degree class of two arts and sciences colleges situated in the city of Coimbatore formed the subjects of the experimental study. A group of thirty of these students taken from one of the two colleges was treated as experimental group 1, while the other group comprised of the remaining thirty students taken from the other college was treated as experimental group 2. An achievement test in AIDS epidemic was administered as pre-tested. The homogeneity between these groups was established in terms of AIDS awareness and attitude towards the AIDS epidemic as measured by the pre-test.

The video programmes on the AIDS epidemic developed by SBS, Australia and National AIDS Campaign, Commonwealth Department of Housing and Community Services, were shown in the experimental group 1, while video programmes on the same theme in Tamil developed by Tamil Nadu AIDS Control Society, Madras, were shown to the experimental group 2. At the end of the video presentation, the achievement test in AIDS awareness and attitude scale towards the AIDS epidemic were administered to both the groups as a post-test.

The same achievement test and the attitude scale were once again administered to both groups as a retention test one month after the experimentation was over.

Analysis and interpretations of data

The responses made by the subjects of both the groups were scored and analysed. The hypotheses were tested by using "t" tests. The mean and SD of the scores on achievement in AIDS awareness and attitude towards the AIDS epidemic as measured by the pre-, post- and retention tests had already been computed for both groups. In order to test the formulated hypotheses, they were stated in the full form.

Null Hypothesis 1

The linguistic and cultural background of the video programmes on the prevention and control of the AIDS epidemic has no influence on media effectiveness in terms of knowledge gain among undergraduate students. To test the null hypothesis, the "t" test was attempted between the means of experimental group 1 and experimental group 2 on the scores of achievement in AIDS awareness as measured by the post-test. The results are given in Table 1.

Table 1: Significance of difference between the means of experimental groups 1 and 2 on the scores of achievement in AIDS awareness as measured by the post-test.

SL.	Experim	ental	Mean	SD	D	TD	t
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No.	Intervention						
1	Video	English	43,06	3,00	1037	0,70	1,96*
2	Video	Tamil	44,43	2,43			

N=1=N=2=30; DF=58; *Significant at 0,05 level

From Table 1, it is found that there is significant difference at 0,05 level between the means of experimental groups of 1 and 2 on the scores of achievement in AIDS awareness as measured by the post-test. the mean value of experiment group 2 was found to be higher than that of experimental group 1. Hence, the null hypothesis is rejected and the hypothesis is accepted. It is concluded that when the linguistic and cultural background of the media materials is close to that of the viewers, there will be a higher level knowledge gain in AIDS awareness.

Null Hypothesis 2

The linguistic and cultural background of the video programmes on the prevention and control of the AIDS epidemic has no influence on media effectiveness in terms of attitudinal development among undergraduate students.

In order to test the null hypothesis, the "t" test was attempted between the means of experimental groups 1 and 2 on the scores of the attitude towards the AIDS epidemic as measured by the post-test. The results are given in Table 2.

Table 2 Significance of difference between the means of experimental groups 1 and 2 on the scores of attitude towards the AIDS epidemic as measured by the post-test.

SL No	Experimental Intervention	Mean	SD	D	TD	t
1	Video	English	122,67	15,98		
2	Video	Tamil	123,63	15,68	0,96	4,09
						0,23NS

N1=N2=30; NS= not significant

From Table 2, it is found that there is no significant difference between the means of experimental groups 1 and 2 on the scores of the attitude towards the AIDS epidemic as measured by the spot test S. Hence, the null hypothesis is accepted as the hypotheses is rejected. It is concluded that the linguistic and cultural background of the media materials does not influence the attitudinal change towards the AIDS epidemic among undergraduate students.

Null Hypothesis 3

The linguistic and cultural background of the video programmes on the prevention and control of the AIDS epidemic has no influence on media effectiveness in terms of prevention of knowledge gain among undergraduate students.

To test the null hypothesis, the "t" test was attempted between the means of experimental groups 1 and 2 on the scores of the achievement in AIDS awareness as measured by the prevention test. The results are given in Table 3.

Table 3: Significance of difference between the means of experimental groups 1 and 2 on the scores of AIDS awareness as measured by the retention test.

SL	Experimental	Mean	SD	D	TD	t
No	Intervention					
1	Video English	38,83	3,21	1,84	0,85	2,16*
2	Video Tamil	40,67	3,35			

N1=N2=30; F=58; *Significant at 0,01 level

From Table 3, it is found that there is a significant difference at 0,01 level between the means of experimental groups 1 and 2 on the scores of the achievement in AIDS awareness as measured by the retention test. The mean value of experimental group 2 was found to be greater than that of experimental group 1. Hence, the null hypotheses is rejected and the hypothesis is accepted. It is concluded that when the linguistic and cultural background of the media materials is close to that of the viewers, there still may be a higher level retention of knowledge gain in AIDS awareness.

Null Hypothesis 4

The linguistic and cultural background of the video programmes on the prevention and control of the AIDS epidemic has no influence on media effectiveness in terms of retention of attitudinal change among undergraduate students.

To test the null hypothesis, the "t" test was attempted between the means of experimental groups 1 and 2 on the scores of attitude towards the AIDS epidemic as measured by the retention tests. The results are given in Table 4.

Table 4: Significance of difference between the means of experimental groups 1 and 2 on the scores of attitude towards the AIDS epidemic as measured by the retention test.

SL	Experimental	Mean	SD	D	TD	t
No	Intervention					
1	Video - English	121,6	15,62	3,6	4,07	0,88Ns
2	Video- Tamil	118,0	15,88			

N1=N2=30; N-Not significant

From Table 4, it is found that there is no significant difference between the means of experimental groups 1 and 2 on the scores of attitude towards the AIDS epidemic as measured by the retention test. Hence, the null hypothesis is accepted and the hypothesis is rejected. It is

concluded that the linguistic and cultural background of the media materials does not influence the retention of attitudinal change towards the AIDS epidemic

Recommendations

On the basis of the findings of this study, it is recommended that

1. The development of the media materials aiming at providing an understanding of the HIV infection among youngsters should take into account the local culture, linguistic features and educational norms of the target audience.
2. In the absence of a cure for AIDS, it is imperative to provide awareness about the HIV infection and its control through effective media which take the message to the target audience within a short period at least cost.
3. Teaching strategies such as role playing, plays, moral dilemma, brain storming etc. may be adopted in creating AIDS awareness among young people.
4. An interdisciplinary team approach comprised of medical officers, educational technologists, extension workers and technical personnel is of paramount importance for evolving appropriate instructional strategies and for the development of the media materials in the context of prevention and control of the AIDS awareness
5. Research efforts may be undertaken to find out which medium is most effective in bringing the AIDS message to the target population and achieving the maximum retention.

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Discussion

F. Bourdier : Right from the beginning you have explained how you selected the different control groups and afterwards you showed us clearly the results. But, how did you proceed for evaluation? You bring us the tools but not the contents. On what did you rely to check information given by the people? What questions did you ask them, if there were at all question? How did you get reliable data between the three different groups you have mentioned? How did you manage to get the feedback from the college students as to whether the awareness programme was effective or ineffective ?

N. Balasubramaniam : Besides guiding MPhil and PhD scholars in Education Technology, I have also undertaken a few major research

projects. Of which one is an evaluation of an AIDS awareness programme sponsored by the Rotary Club International. Moreover, one of my PhD scholars also has worked on instructional media on AIDS awareness. My paper was on the influence of the linguistic and cultural background of media materials on media effectiveness in the prevention and control of the AIDS epidemic. As I have already stated, we wanted to know to which extent the video programmes from different agencies developed by both international (Rotary) and national agencies (TNSACS) were adequate to the rural and urban population. Apart from the video films, dramas were acted out among the undergraduate students of colleges situated in Coimbatore City. Effectiveness was verified through achievement tests. It is nothing but testing their understanding and their knowledge and how they apply it to the given situation in such a way that the items in the achievement spread over the different levels of cognition, i.e. mental development. Not by questionnaires, but by test papers which we call "achievement tests".

Dr Shukla : Were the questions and answers of an objective or of a descriptive type ? Your work was on the linguistic and cultural background, so we would like to know to how many people you administered questions in English and to how many people in the local language ? What was the difference?

N. Balasubramaniam : They belong to objective type questions. I have not brought the questionnaires with me, but I can cite some examples. A statement made like: HIV spreads through the following, and three choices are given. The respondent has to select one answer. Out of the three statements, only one is correct and the respondent has to choose the correct one. So there are about 75 such questions with multiple choice answers. From the linguistic point of view, the question paper was in only English, insofar as both the groups were English medium students.

Dr Shukla : In that case, there is no question of any linguistic background. If there is a difference of questions administered in English and in a local language, you can find out the difference of the impact.

S. Surender : One video was in English and another in Tamil.

Mehboob Dada : The question is about the linguistic and cultural background. If we want to target individuals we have to show materials which might be appropriate to them. I suspect that it might not be appropriate to show these materials to students in Tamil Nadu. and you might have arrived at the wrong conclusions and maintain them for the purpose of argument and debate. So I think we have to be careful when we are doing this sort of pre-testing to identify materials that would be appropriate for students.

Prof. Gurumurthy : To sum up, there are some materials prepared for the Australian audience. If you brought them and showed them to the Indian audience the results can be doubtful. In the same respect, it seems you do not know whether the same age group was selected. You wanted to know whether the materials could convey the message to the Tamil audience or not. It is a very valuable question which raises the problem of cultural and linguistic differences. But in order to know the comprehension level of these messages, you have employed an achievement test, on the basis of which you evaluated whether the messages were conveyed to the students or not. If not conveyed, the cultural and linguistic factors are put forward and you deplore that it should have been taken into account. That is what you wanted to find out. But the research should have gone a bit deeper, first by explaining clearly what you mean by cultural factors and then, how they were integrated from the beginning in the video materials. The same applies to the linguistic components. There is a paradox somewhere because there is a lack of proper definition.

Sociocultural Dimensions in the Transmission of HIV/AIDS in Karnataka

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Introduction

AIDS is spreading alarmingly to almost every part of India, and the state of Karnataka is no exception. The first case of HIV was reported in the year 1987. According to an official report of the State AIDS Cell, the total number of HIV-positive persons was 3115 as of June 1997. However, unofficial estimates put the number at more than 50,000 in the whole state of Karnataka. The increasing number of persons with sero-positivity and AIDS is posing an unprecedented challenge to all those involved with the medical, social, psychological, ethical and legal aspects of the problem.

Governmental as well as non-governmental agencies are working with prevention and awareness programmes in the state. However, there is not much co-ordination and co-operation among these agencies. Few NGOs in the state are in the field of giving care and ongoing support to HIV-positive persons. Bangalore is privileged to have three organizations working specifically for the care of HIV-positive persons.

Given the traditional cultural and religious background of the people of this state, an HIV-positive person, or one who has AIDS, has to face the physical agony of the disease, emotional and psychological stress, social discrimination and even rejection by family and society. In this paper I would like to focus mainly on the sociocultural aspects which further the transmission of HIV in the state of Karnataka. The names used in the cases to which I refer to substantiate and clarify certain points are pseudonyms.

Sociocultural factors affect the lives of the individuals in society and influence risk behaviour in several ways. Society provides the context in which types of behaviour are shaped and conducted. It is society which determines to a great extent the particular social environment in which an individual lives. The structure of opportunities, the available role models, the social norms perceived, the beliefs, attitudes, values and the self-perception of an individual are for the most part influenced by his/her social environment and in turn affect his or her behaviour.

It is well established that HIV is transmitted mainly through sexual contacts, exchange of blood and blood products and vertical transmission from mother to child. I would like to focus on some of the sociocultural factors which further the transmission of HIV in Karnataka.

Sociocultural factors which further the transmission of HIV through sexual contacts

In Karnataka, about 80 per cent of those who are infected with HIV contracted the infection through sexual contacts. As one of the major modes of transmission, I would like to discuss this point on several levels.

Sexual life of married couples

Sex life within marriage is controlled by several outside factors. Ideas of auspicious and inauspicious days, long abstinence during pregnancy and child birth minimize the number of days when husband and wife can come together sexually. The avoidance of coitus associated with religious festivals and fasting days is quite common in the rural areas of the state. For example, the period of abstinence during the time of pregnancy and child birth usually extends from six months to one year in rural areas, whereas in urban settings this ranges from three to six months.

It is expected that with age the sexual drive will reduce in men and more so in women. Since this is neither a biological nor psychological fact, couples may undergo long periods of abstinence due to lack of privacy as provided by familial roles, as well as lack of desire from the other spouse. However, research indicates that men as well as women often desire the continuation of a sexual life after the generally prescribed age. Since this is not socially accepted, abstinence in marital relationships can occur, leading to sex outside the marriage. For example, take the case of Mohan, who is over 65 years old. He was tested positive last year. After the age of 62, he used to visit CSWs because his wife was not co-operating with him to have sexual union. This attitude of his wife forced him to search for sexual pleasure outside the home and this resulted in his becoming infected.

In the urban areas, there are some other factors which restrict sexual relations. The acute shortage of adequate housing facilities prevents the couple from having the necessary privacy. Children and other house guests from their native places make privacy more difficult. The

situation narrated by Chidambaram is illustrative. He and his family live in one of the slums of Bangalore. They have only one room which is shared by eight family members. Most of the days, there was no opportunity for him to have sexual relations with his wife because of this situation. So he began to go outside, especially to CSWs, for sexual gratification and in that process acquired the HIV infection.

The stress and strain of modern life also has its effect on the sexual life of married people. The demands of their workplace, such as factories and hospitals where they work according to shift systems, keeps husband and wife apart for many nights and subjects them to forced celibacy. Then, when one of the spouses stays far away from home due to his/her employment, forced sexual abstinence is inflicted on the other spouse. When these persons have an opportunity to fulfil their sexual urge, they easily fall prey to the occasion. An example of this situation is Ravi, who was in the military and was posted to Jammu three months after his marriage. For almost a year he could not return to his home in the South. Now and then he visited the local girls in the nearby villages. This year he was tested positive during a routine check-up.

Pre-marital sexual relations

Pre-marital sex has never been encouraged except in certain tribal societies. Youth experience a sexual crisis in their teens. Lack of opportunities for sexual experimentation and absence of proper knowledge leads to the discovery of sexual matters through literature and actual experiences with prostitutes, friends and relatives.

Sex is fascinating for youngsters whose opportunities for mixing with members of the opposite sex on a social level are few. The observations of different studies suggest that youth in this state, when given the opportunity, begin to experiment with sex at an early age. Recently, another trend has been observed in city life. There are "pubs" to which young boys and girls go in the evenings to drink and dance together. This extends late into the night and can lead to sexual experimentation.

Extra-marital sex

Sex outside marriage, in Karnataka and in other states of India, has been viewed differently on the basis of gender, religion and other such variables. Islam punishes adultery by women harshly, but allows it for men by permitting polygamy. The attitude of educated men and women towards extra-marital sex is slowly changing, especially in the city areas.

Opportunities for heterosexual relationships outside marriage are less frequent for women because of the cultural constraints on them and their physical restriction to the household. But one cannot rule out the possibility of extra-marital sexual encounters in the case of women who live alone in the villages while their husbands are in the cities at work, and are thus sexually deprived. Some of the women in the following categories are in a way forced to engage in extra-marital sex:

- women who have sexual demands made on them by those in socio-economically powerful positions in the community in return for favours, concessions and employment ;
- women who are dissatisfied with their marital relationships due to the absence of romance, dissatisfaction in sexual experiences, sexual repression and other reasons related to their sexual life ;
- women who are victims of rape.

Men, on the contrary, are known to indulge in sex outside marriage for the following reasons:

- during periods of abstinence ;
- when one's wife is ill or away ;
- during the wife's pregnancy and child birth ;
- for variety on special occasions ;
- when the man is away from home, working in or travelling to distant places ;
- in order to experiment with different positions in sex or different types of sex which may be refused by one's wife ;
- when the man feels that his wife is not co-operative.

These and other reasons may lead men and women to search for sexual gratification outside marriage, by visiting CSWs and others who are ready to give sexual pleasure.

Cultural ethos regarding sexual education and sexual health

According to the cultural setting in this state, discussing or talking about sex openly is not well appreciated. Sex education experts strongly suggest that explicit sex education will improve the overall health of adolescents.

Studies indicate that young people want to know more details about the physical and emotional aspects of sexuality and complain that current efforts are not providing such information. Recently, the principal of a reputed English medium school told researchers that sex education in schools would imply information about sex differences, the development of sexual characteristics, reproduction, and focus mainly on the psychological aspects. But during such classes and courses, the students are not taught about love, marital rules and relationships, sexual hygiene or STDs/AIDS.

The approach to sex has been moralistic, restricted to reproductive purposes. Very little emphasis is given to providing correct and adequate information and preparing men and women for sexual life. Values related to sexual behaviour are also developed in a gender specific manner and perpetuated via myths, folklore, creative arts and popular literature.

Presence of commercial sex workers

Commercial sex workers need special attention in the context of AIDS because of the multiplicity of their sexual contacts and high STD rates. In the cities and villages of Karnataka, there are also many who live by the sex trade. As in Mumbai, they are not organized and do not enjoy the full returns of their labour. Their entry into this occupation is often the result of coercion by cultural, religious and economic factors.

The *devadasi* system is one of the religio-cultural factors which forces young women to sacrifice their virginity in Karnataka. This practice involves the dedication of young girls and women to the goddess Yellamma. Through this practice, hundreds of young girls are made to spend their lives outside the marital framework, but in a sexually connoted situation. Many of them are compelled to take up prostitution either on a regular or a part-time basis. Most of these girls go to Mumbai and work as CSWs for months or years and then return to their villages.

Because the families of these girls live on their incomes, they are in no way allowed to stop their business. If they come back abruptly without the permission of the family members, they are not appreciated and will be at the mercy of others. Being unaware and uneducated with regard to STDs and the HIV infection and the necessity of condom use, these girls become easy prey to the AIDS virus.

Homosexuality in Karnataka

Homosexuality was a taboo subject until the HIV panic hit the country. It is publicly acknowledged today that homosexuality exists as a way of life in different parts of India, including Karnataka, for example in the cities of Bangalore, Mangalore and Hubli. The main reason for homosexuality is the availability of men instead of women in a society where women are not encouraged to interact with men socially.

A large section of this group is bisexual. Such men adopt occasional homosexual liaisons due to the non-availability of alternatives or because of inconvenience. For example, truck drivers who have sex with young boys who work as cleaners on their trucks, prisoners who engage in sex with fellow prisoners, young men in hostels or male dormitories and men who live collectively away from their wives, are all prone to seek sexual gratification among themselves.

In the wake of the HIV infection, anal and oral homosexual acts can easily lead to the transmission of the virus from an infected person to his partner.

Street children

Like any other place in India, street children are plentiful in the cities and towns of Karnataka. They emerge as a group vulnerable to AIDS owing to their special characteristics. Sexual exploitation by older boys, men and women, in return for money and favours is also common. A number of children are initiated into drug and alcohol abuse at an early age and even visit CSWs or take up commercial sex themselves. Fighting for survival on a day-to-day basis, they are not likely to be concerned about becoming infected "some time" in the future. This in turn may make them indifferent about preventing infection and thus vulnerable to the HIV infection.

The researcher met at least three such children who are already infected with HIV and are cared for at a centre. A good many of them become "children of the street" as a result of sociocultural factors. Most of them are children of CSWs and several others are orphans who

live at the mercy of others. There are a few on the streets who, because of strict parental control, came out to enjoy freedom. Often these children have to support themselves and their younger ones also. If the government and society would show sufficient concern, the number of street children could be reduced.

Blood and blood products as modes of transmission

According to statistics provided by the State AIDS Cell, 15 per cent of all HIV transmission is resultant of blood transfusion. There is a continuous shortage of blood, due mainly to the past reluctance of people to donate blood. This reluctance ensues of the fear of loss of vitality and health due to the loss of blood. This mentality is deep-seated in some societies. During surgical procedures, there is also a wastage of blood. Medical personnel must be made aware of the rational use of blood during such procedures.

The case of Johnson illustrates how innocent people become infected because of carelessness in blood transfusion. He met with an accident and was severely wounded. Because of profuse bleeding, he was in need of blood, and five bottles were transfused. This was done in a well-known hospital in Bangalore. Six months later, his blood was tested and found to be positive. His own family members doubted his moral integrity and his wife left him, saying that he was insincere and unfaithful. This is but one case. How many other Johnsons face the same fate?

Needles and syringes as sources of HIV transmission

People from all walks of life perceive injections as a necessary form of treatment. The medical profession is also highly oriented towards injections as they symbolize technical supremacy.

The notion of disposable needles and syringes has not yet been accepted by medical and paramedical practitioners in view of cost and availability factors. More importantly, the psychology of scarcity in developing countries leads to the refusal of everything which cannot be reused. Disposable instruments are still inadequate, and there is always a possibility of reuse. If necessary precautions are not taken, needles and syringes used in hospital settings can also become sources of HIV infection.

Other skin-piercing procedures

Non-surgical skin-piercing is common to all South Indian societies. Some of these are ritualistic, such as circumcision among Muslims. Some practices are cosmetic in nature, like tattooing, nose and ear piercing. These practices are widespread and little is known about the conditions under which they occur. In the wake of the HIV infection, people must be cautioned about the need to sterilize the instruments used for piercing.

Intravenous drug use

The sharing of needles and syringes used to inject addictive drugs is well established as a practice which spreads the HIV infection. Drug addiction is becoming popular in South Indian cities, and Bangalore is no exception. Only a few cases of HIV have been reported to have been transmitted through needle-sharing during drug use. Since drug addiction is becoming more popular among the youth of South Indian cities due to the exodus of drug smugglers from Manipur to the South, special care must be taken to educate teenagers about the dangerous aspects of drug addiction.

Perinatal transmission

Perinatal transmission is also going to be a major problem in the state of Karnataka. Women who are CSWs, those in the hotel/tourist/travel and entertainment industries, women who are wives/sexual partners of STD patients, male IDUs, clients of CSWs, are at risk of contracting HIV. It is impossible or unethical to test all these categories of people.

Currently it is suggested that HIV-positive women be advised to avoid pregnancy, or if pregnant, to opt for abortion. Different societies in Karnataka consider progeny to be a blessing from God, and barrenness to be a curse from God. Thus married couples always like to have children, and death is preferred to remaining without a child. Because of this, it is difficult to convince couples not to attempt to beget children if either partner is an HIV carrier. Abortion is still a controversial issue because some of the communities, such as the Catholics, do not approve of it.

Recently, a child of one and a half years was admitted to one of the hospitals in Bangalore because of fever and cough. When, after a few days of treatment with no improvement, the blood of the child was tested, it was found to the dismay of the medical personnel to be HIV-positive. Following interrogation and counselling, both parents were tested, and were also found to be positive. Such instances are certain to occur more frequently in the future.

One solution to this would be that those who were or are involved in risk behaviour are tested for HIV and are careful in their relationship with their own spouse or sexual partner, and that condoms are used if either partner has the HIV infection.

Intervention strategies

Intervention strategies must be designed with consideration to the above-mentioned and other sociocultural factors involved in the transmission of HIV. Following are some suggestions which, if put into practice, would be able to curtail the spread of the HIV infection in Karnataka, as well as elsewhere in India.

- In present society, sex for progeny is seen as the purpose of marital sex, while sex for pleasure is viewed as being outside marriage. It therefore becomes essential to project sex in marriage as enjoyable and pleasurable to men and women through sex education efforts. Emphasis must be on the emotional fulfilment of sex along with the physical aspect. An approach which advocates monogamous relationships and which provides safe sex and family harmony without a moralizing tone is praiseworthy ;
- It is necessary to launch a serious campaign concerning STDs, their prevalence, transmission and prevention, removing misconceptions. Such messages must ensure coverage of different age, sex and socio-economic and the common masses, and specifically among those who indulge in high-risk sexual activities ;
- The necessary awareness and education programmes should be conducted among societies and religious sects which support systems such as the *devadasi*-s in which young girls are forced to sacrifice their virginity for the sake of religious convictions and practices ;
- There is an urgent need to conduct inspections of all commercialized blood banks and identify unlicensed blood banks in order to promote the use of HIV-free blood ;
- Testing kits which are easy to operate should be provided to all blood banks and a national-level blood policy implemented to improve the availability of HIV- free blood in all regions ;
- Youth should be educated with regard to the danger of using drugs, especially of sharing needles and syringes. Parents and teachers have to pay special attention to this.

Discussion

F. Bourdier : One has to be very careful about what we may call quick statements which implicitly provide wrong relations, correlations or causative relations between two factors. For example, you mention young people who are going to the pub in Bangalore and who afterwards will go together to have sex and will contract AIDS. It is important to be careful when we say such things. I go to the pub whenever I can, but it doesn't mean that this kind of chain that you are suggesting exists. As researchers, we may be tempted to make recommendations because it is something that is advisable and we are also willing to provide a sociological dimension. But recommendations cannot be mere prescriptions. A social scientist cannot make the sort of recommendations like the ones given by a doctor.

S. Sureender : In a similar perspective, anecdotal facts remain casual by definition. The case of a sixty-two year old man is a very rare phenomenon. If it were a common phenomenon, it would be of more interest. The rarity of getting infected at this age is a matter of fact. Otherwise, the data would show that people above 60 are infected and not in the 30 year age group. I don't think we have to give it so much importance, unless he went on infecting many people. Maybe we shouldn't be attaching more attention to sexual experimentation at a post- retirement stage. The important aspect in research is to pose correctly the problem and to allow new ideas, new facts to be inserted.

Prof. Gurumurthy : Sex, according to anthropology, is cultural and not biological, especially for Indians. But psychologically, the man Father Jose was talking about was not old. He was active sexually and he did not get the co-operation from his wife due to lack of privacy, and if they were caught, the insult and the shame would fall more to his wife than to him. Because for this person, it is matter of being still very active and demanding. The presenter is an anthropologist, and there are more ways of explaining an issue: medically, psychologically, socio- anthropologically.

Dr. Jaysankar : You speak about pubs in Bangalore, but going to bars and dancing and then going for sex is particularly common in Pondicherry, even if the contextual situation is very different. In all streets of Pondicherry, there are three to four bars and there are fellows doing pimp work. They wait outside the bar and as soon as a drunkard comes out, he is dragged to a red-light area, convinced to have sex and whatever money he has is forcibly taken away. This particular point has to be taken care of in Pondicherry. Another issue concerns blood : at the medical college of Pondicherry a person who came for a duodenal emergency operation had five well-built healthy sons who all refused to donate blood for him. Finally, they went across the road and caught hold of a rickshaw puller who was a professional blood donor, and without testing his blood, it was transfused to the in-patient. This happened about five years ago, and the person got HIV as a consequence of blood transfusion. I feel that the NGOs, while giving health education, can also build up a register of blood donors, such as young people in high school and college. Many of them who are patriotic can be motivated to donate blood. NGOs have a very important role to play in this. They can have private blood banks and blood registers as is done in foreign countries. Here, on 15 August and on Republic Day and while celebrating the fiftieth year of independence, we had a blood donation camp. In Pondicherry, we could have another camp on French Independence Day, 14 July; the 5000 Indo/French people can donate blood.

Male respondent : Many times, the patient bleeds for a long time and the blood to be transfused cannot be tested quickly. Efficiency with security is a problem in case of emergency. There is a gross negligence on the part of the medical professionals.

Prof. Gurumurthy : Usually, patients have to pay for the blood they receive. There are additional charges and we cannot criticize this. Regular medical professionals, who are trained, are all right, but there are sometimes quacks who run blood banks and do not take normal precautions.

Dr. Jaysankar : What do you mean by quacks ?

Male Respondent : Here in Tamil Nadu all the banks have to be registered. There are very stringent rules on this.

Dr Subramanian : As a person involved in voluntary blood donation for the past 30 years, I would like to state that in Madurai, in Tamil Nadu, the teaching hospital does not take commercial blood. This is something very good. But when you come to the private sector you see the volume of blood that is available to rich patients, but the quality cannot be guaranteed. The answer is that not only in Tamil Nadu, but also in other places, it is high time that voluntary blood donation is extensively propagated. We have blood banks that really stand the test of modern methods. A man at the receiving end who is prepared to pay should not receive blood that is contaminated.

Prof. Gurumurthy : Already all hospitals have a list of blood donors. These are mostly Rotarians, Lions Club members and such voluntary organizations which give a list of blood donors .Whenever there is need, they are called by telephone and they donate according to the need

Rajasekhar : The blood grouping has been done to all students in Tamil Nadu who are in the NSS. If I want blood, I can go to any college or school and they put it the notice board : on that very day, I can get the blood.

Dr. Jaysankar : It has been brought out that most of the blood is checked for hepatitis B and HIV, but there are other diseases like hepatitis C. To the best of my knowledge, hepatitis C is not checked. There was an editorial in the Hindu (a daily newspaper) in which they have

mentioned 15 blood banks in an area near the bazaar where only four have the facilities to check for HIV. In the rest of the places, both the rich and poor people get blood without it having been checked for HIV.

Dr P.K. Das : The NGOs who are working now can educate the people that if you donate blood the risk of getting cardiovascular disease is reduced. That can be one of the ways of motivation, why not. One has to stimulate the people.

Dr Jayasankar : Let us talk about the disposable needle and syringes. This problem is being faced not only in the government hospital of Pondicherry, but also in private clinics and in other parts of the country where they do not have concrete programmes on how to dispose of these disposable needles and syringes. Could you tell us how responsible doctors in Chennai are handling this problem ?

Dr P.K. Das : It is again the irresponsibility of the people; not only the doctors, but all are responsible for this problem. In fact, in my own institute, we have been taking hundreds of samples and I have been saying that unless we dispose of them in a proper manner, they will pose a problem. But, leave needles aside; how do you even dispose of disposable cups ? They are also used daily and must be disposed of.

Dr Shukla : Recently, a verdict of the Delhi High Court was to the effect that plastic should not be disposed of because it is harmful to the environment. So people do not know how to dispose of the plastic disposable syringes. The Delhi government is now distributing inclinators.

Dr Gaikwad : Regarding disposable needles and syringes, there is a misconception among the medical professionals. Disposable syringes and needles are not biodegradable. They are going to create environmental hazards in the near future. But they need not be advised as a part of the HIV/AIDS control programme; the routine metal needles and glass syringes can be advised. The HIV/AIDS virus is very sensitive and will be killed if boiled for just one minute. We advise that syringes and needles be boiled for thirty minutes to kill other organisms. So there is no risk of the spread of HIV/AIDS by using glass syringes and needles and disposable needles and syringes must not be used.

Part Five :
Giving a voice to the
people living with HIV and AIDS
and to
the organizations involved
in care and support

Social Work Techniques for Helping Persons with HIV/AIDS

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This paper is an attempt to present a brief overview of techniques used in social work practices to help persons living with HIV/AIDS.

The AIDS epidemic cannot be viewed as a mere medical problem alone ; the spectrum of AIDS has many dimensions and there is an urgent need to view it from the psycho-social and developmental perspectives. It has been felt that persons living with HIV/AIDS (PLWHA) form an increasing client group in need of social work services. Social work is a human service profession which seeks to help people meet their needs (psycho-social) by using the elements in their social environment (family, friends, social groups, other professionals and organizations), as well as their own economic, emotional and intellectual resources. Social workers intervene to help individuals, groups, or communities. Simultaneously, they also contribute to policy development, programme management and research into various social problems and services to ameliorate them. Social workers in health care settings, especially those who provide care services for PLWHA, deal with the social, physical and psychological aspects of these persons in their treatment and convalescence. Social work services are usually addressed to three levels and are considered as methods of provision. These methods are addressed to individuals, groups and communities.

Social work with individuals

Working with individuals, technically known as social casework, is the oldest method of social work. The aim of social casework is to restore, reinforce or refashion the psycho-social functioning of individuals and their families who are having trouble in their personal, interpersonal or situational encounters. Social casework provides a well-defined method for helping PLWHA in dealing with their psychological and social problems which relate to their daily life. The social casework process can help PLWHA to accept their HIV-positive status, to understand the implications of being HIV-positive, to develop a new outlook towards life as a HIV-positive person, and help them to lead a responsible life.

Preparing a person for the HIV test, revealing the diagnosis to the individual, and if positive for HIV antibodies, working out a follow-up programme for the individual along with his/her significant others, needs to be done through the casework process in combination with counselling. HIV/AIDS counselling is seen as an ongoing dialogue and relationship between client (PLWHA) and counsellor, with the aim of preventing the transmission of HIV and providing psycho-social support to those already affected. In order to achieve these objectives, counselling seeks to help infected persons make decisions about their life, boost their self-confidence and improve family and community relationships and the quality of life. HIV/AIDS counselling also provides support to families and loved ones of the infected persons, so that they in turn can provide encouragement and care for those with HIV/AIDS. Counselling and casework services are necessary because PLWHA may be faced with fear, guilt, anger, depression, social isolation and rejection, adjustment to disease, and anticipation of death. By addressing the above concerns, caseworkers can facilitate reconciliation among family members and significant others, encourage patients to discuss their health problems with physicians, help PLWHA to participate in social activities and support groups, teach stress management and relaxation techniques and encourage them to follow a nutritional diet.

Social work with groups

Working with groups, or social group work, is a method of social work through which individuals are helped to participate in the activities of a group for their emotional, intellectual and physical growth, as well as for the attainment of socially desirable goals of the group. Social group work is a way of serving individuals in groups in order to bring about a desired change in clients (PLWHA). The group is viewed as a small social system which is utilized to help clients develop abilities, modify negative features of their self-image, resolve interpersonal conflicts and find new and more constructive patterns of behaviour. Social workers should help PLWHA to seek support and develop their support networks through their existing social networks of significant others, family members, friends, relatives, work associates, other professionals and self-support groups. Social workers who practice social group work as a method should plan group formations with PLWHA, facilitate the group members to express themselves freely and share their problems with one another, thereby fostering mutual acceptance within the group. The group worker should guide the interactions of the group members and influence the dynamics of the group in programme activities and group tasks to bring about a positive growth among the individual members to achieve desirable social goals. Problems of persons with HIV/AIDS, such as fear of contagion, fear of social isolation, homophobia, hypochondria and problems related to behaviour change, such as resisting and relapse of risk behaviour, can be effectively handled in a social group work situation.

Social work with communities

A method of social work known as community organization is the process of creating and maintaining an effective adjustment between community resources and community welfare needs. It is achieved through the participation of individuals and groups in the community by planning and developing social services in order to meet the health and welfare needs of the community. Community organization as a method should be used to mobilize community resources to meet the needs of PLWHA in such a manner that resources are provided without discrimination in the community. The community organizer should find ways and means of dealing with communities concerned with social welfare services to participate in HIV/AIDS programmes to reduce the spread of HIV and to provide care and support for those infected and those who are in their terminal stages. The community organizer should identify the actual and felt needs of the risk groups and the community, co-ordinate the existing services and introduce new and effective services in the community. In so doing, the community organizer promotes better public understanding of welfare services for the HIV infected and affected persons.

Leaving with HIV and AIDS in Indian Society : strategy for networking

Rama Pandian, TNP+, Chennai (Tamil Nadu)

My name is Rama Pandian, founder, member and co-ordinator for the Tamil Nadu Network of Positive People. I am not a doctor or scientist or great personality to deliver a lecture here. I am a simple and ordinary person like anyone else. I have a horrendous experience in my life to share with you. So we come together in the second decade of a most unexpected and horrible epidemic that has taken away mothers, fathers, brothers, sisters, children, friends and lovers.

It was in 1992, I was basically a paramedical person working in a hospital that I will not mention. I was asked to donate blood, as I was working in the biomedical lab department of the hospital. Three months after having given the blood donation, I was having coffee at the canteen with my colleagues, and one of them told that my blood had been tested and screened positive. I could not at all believe it. He asked me to go for confirmation. In the meantime, during these three months, all of my other colleagues, such as nurses and doctors, came to know of my status without me knowing. I was the only one to be uninformed. First, the same sample was sent for confirmation and the administration also asked me to come in person to be given the confirmation test. So I went to the Madras Medical College Microbiological department. At that time, they asked me about my family background, my sexual activities, whether I used to go to visit prostitutes and other meaningless things. They took my sample and urged me to come after four days. What happened was that even before I knew the result, the medical officer of the hospital where I was working requested the result over the phone and the lab gave the result without any reluctance to him by phone. Naturally, I was unaware of that. In fact, a big agitation was going around me, about me but without me. Later, the medical officer came to me and said that my sample had been tested and found again positive. At that time, I believed that when I was given the test for confirmation, it would come out as negative.

When I came to know the definitive result, I could not believe it. It took me a long time to accept the fact that my blood had been screened as positive. Immediately, my medical officer called me for a personal discussion and asked me different questions, such as how many women I had had contact with. At that time, I felt that their attitudes towards me were very bad and indecent. I was not able to reply even a single word, because of the feelings and emotions that I had. Using this situation of my emotional feelings, they forced me to sign my resignation letter, and I did it on the spot. Nevertheless, I had no choice and they were ready to use all kinds of constraints to throw me out of the hospital.

I did not know what to do after that. I went to the room where I was living with three bachelor friends working in Chennai. For three days, I did not go to work and subsequently my room mates asked me why I was remaining idle. I replied that I had taken leave. I had not been eating properly at that time. Seeing this, my friends asked me what was wrong. I was so choked with the news that I was not able to express my feelings and emotions to anyone. I was already facing isolation and I was frightened about everyone's reaction. Finally, I informed them about my seropositivity, but they did not believe at that time.

I was not going to my native place and, anyway, there was no point sharing my feelings with my family. A few days later, I read an article by Dr. Jayashree on HIV which had been published in "*Junior Vikatan*", a popular Tamil magazine. I read it and I started collecting all the articles and reports regarding HIV which appeared in different publications. I came across an article of a

person with a positive status who came forward in public and expressed his views. I was impressed by his statement. How did he have the courage and where did he find the force to enhance himself in such a way ? Then I happened to meet Dr. Sunnithi Solomon who was the first to counsel me. This gave me a little hope for my life. I told her that I had been expelled from my job. She also got upset regarding my loss of work and about the attitude of the administration. Then she called me to work with her and I started to work along with her. Dr. Sundraraman, a colleague of hers and director of an organization, counselled me as well.

Initially, I worked with outreach programmes for industrial truck drivers. As I was a lab technician, I did not know about social problems and the engagement of a social worker. I was completely ignorant about the contribution of social scientists in the field of HIV/AIDS prevention. Then, YRG was formed by Dr. Sunnithi Solomon and I was involved in that organization. I worked on the awareness programme in schools and colleges and slowly moved into the counselling programme. It was high time to meet positive people, to bring them to share their experiences and to interact more with the infected population, insofar as nobody was interested in them.

At that time, I got an opportunity to go to South Africa, in March 1995, to the 7th International Conference to which four positive people from India had been invited. I met there a lot of people from all over the world. More than seven hundred people participated. Among them, a lot of positive people living more than seven or eight years with the virus were present. Undoubtedly, it gave me strength. I realized while mingling with them that I was gaining confidence and that possibilities of delaying the disease were there. The whole inspiration pushed me to think about starting an organization for the Tamil Nadu Positive People within the limit of the state, at least in the beginning.

I talked with the positive people who were reluctant to come and meet me. They felt that if they were to come to the meeting, the other people would learn of their status. Initially, I faced this kind of problem in trying to bring them together. They did not want to become a group because a group would be more visible. Slowly, however, I moved informally among them. Then we came together and founded, in 1995, the Tamil Nadu Positive People association.

I wanted in the beginning to take steps with the objectives of improving the quality of life of positive people, of strengthening the network, and of bringing together the positive people, even those who did not want to be part of the group. As I said, the purpose was to share experiences and to develop confidence regarding what we were doing. We educated the positive people as to their rights and helped to the form a self-help group. Before that, I did not know the value of my life, neither as a positive nor as a non-positive person in society. I feel now how much I am valued by a particular community. I am now more strong, bold and courageous. I learnt life living with HIV positive people.

In the same way, I want to teach other HIV people the value of their lives, and to share my training with others. Now, I am strengthened in my social environment which I had adjusted little by little. I am practising yoga and meditation which are helping me a lot. I am very cautious about my food habits, I try to take regular meals and balanced nutritional lunch. The moral dimension is important, and I actually believe that I have more love, care and concern. I make the people of my organization as my main priority. Before, I never knew that life was worth living with pleasure in the right way. I noted that many common persons were talking about the positive people who had a great horrible disease called AIDS and who transmit the infection to other persons, and that

AIDS is a disease to be afraid of. Conversely, the infected people have three major fears : fear of loneliness, fear of pain and fear of death. These are the feelings all of us have. We should feel free enough to share information on how to cope with practical and sometimes burden some issues of living, like daily expenses and income needs, home-help needs, accommodation needs, work needs, spiritual needs, and care needs. These are essential for all to be aware of their own feelings, values and moral outlook.

While realizing that the people living with HIV may be very different from each other in terms of reaction, we are always outside society. But we also have to hope for a change. It is human to hope. The question is how to have access and how to solve the problem of affordability - which are very important. We have no more precious friends, but we live in hope. We need food for the body. In the same way, we also need love for our soul. Compassion is the best form of love. All the people living with HIV need compassion, but basically we are here because of love. We think of precious friends that we have lost. People living with HIV tried to show themselves that everyone can be master of his or her own destiny. Positive people know deeply what it means to shrink day-by-day with the disease, as we know there is presently no cure for it. We advocate self-work, self-care, and self-determination. We do not want to be dependent on society. Positive people need a cure to determine their own life in the future.

I thank all of you for giving me this opportunity to share my experience; more important, inviting me to talk about my own status shows an improvement in the acceptance in society. In India, such opportunities are still lacking. We have to create greater acceptance in the social and professional environment for the people living with HIV. In the future, I hope that the people will co-operate with us. For the first time in India, through TNP+, we have brought out a magazine in order to improve the quality of life of people living with HIV/AIDS. We concentrated on three areas: nutrition, self-care practices and safe sex practices. We also stress management through simple physical and spiritual exercises and yoga. The magazine has appeared in four South Indian languages, Tamil, Telugu, Malayalam and Kannadiga. Whoever wants a subscription can write to our address. I have some copies for your attention and consideration which will be given at a low price to individuals having AIDS and other organizations providing care.

Discussions

Dr Subramanian : Thank you Mr. Ramapandian. You have left some questions unanswered. I don't know whether it is deliberate or not. Are you still positive?

F. Bourdier : What is the point in asking this question ?

Dr Subramanian : Because something can be done. Have you taken any treatment ? If not, you are an ideal case for the treatment and if you continue it for a year, the seroconversion may occur at the end of the treatment. If you continue two more years you will be totally negative. I just express the matter. If I am wrong, please correct me. We, the Indian Society for Environmental Health (ISEH), can help Mr. Ramapandian if he accepts.

Ramapandian : Actually this is the crucial question. Most of the people who are living with HIV/AIDS were tested to know about themselves. Wherever a cure is announced, infected persons go in search of a medicine. I also tried some medicines in the beginning, from *siddha* and other alternative drugs, but these did not produce any results.

Dr Subramanian : I am not talking about *siddha* medicine. I am talking about modern medicine and the mullet-therapy.

Ramapandian : Available drugs of modern medicine were advised, but homeopathic medicine was not advised. Only recently, a combination of therapies came out, but the problem is that of the accessibility of the drugs and their affordability. I am taking care of myself, mainly through yoga and proper nutrition. I am just answering the questions you have asked me : I have been prolonging my quality of life without any problem for the past six years. I have been surviving without any major problem. I expect to continue to live with the same quality of life. If the government is ready to offer drugs for the people living with HIV/AIDS free of cost, or at least at the cost price or at the lowest price, I would want to try, naturally.

Dr Subramanian : Certainly, you prefer to get various medication, not exclusively a treatment issued from multi-drug therapy. If you are willing, we as a voluntary organization can make the first step for getting the drugs to people like you.

Dr P.K. Das : That is a good intention. But there are hundreds and hundreds of HIV patients. How many will you select and how can you go on to give the drugs ?.

Dr Subramanian : We already had the idea of drug provision. Why not start with Ramapandian ? He is the person to have appealed for this in a different way.

Dr P.K. Das : I don't think he has appealed to you.

Dr Subramanian : I am just making a suggestion. Nobody will be forced, of course.

Dr P.K. Das : Ramapandian is telling you to respect him. He is an individual and he is taking care of himself and his friends. You should congratulate him on having established a network and started fighting for human rights.

Dr Subramanian : He says that he is practising yoga meditation. That does not exclude the multi-drug therapy. He has not frankly told us that he doesn't want any treatment. Would you please answer that question Mr. Ramapandian. Because people in the assembly think that I am forcing you to do something.

Ramapandian : I do not take AZT due to my economical position. I am not able to meet the cost of the medicine. It is also important that everyone who is living with HIV/AIDS is informed about his body's acceptance of the drugs. There are lot of side- and toxicity effects. The anti-retroviral therapy has not been proper. However, management care has been taken in our places, especially in India. In particular the CD4 counts test has not been available. You will not have all the parameters for proper medication and proper follow-up. It is, however, needed. A proper diagnosis should be possible for everyone.

Dr P.K. Das : The cost per kit is about 15 000 rupees per patient. Secondly, the toxicity is very high and there is a lot of allergic reaction to this type of drugs. Thirdly, according to the latest medical research, the efficiency of the AZT is even called into question today. India should not be the depository of Western drugs which are not unanimously recommended.

Dr. Subramanian : If you take a drug called metroindosal, you get stomach pain and vomiting. Would you recommend the banning of metroindosal because of this ?

F. Bourdier : I have to remind you that we are not there to discuss therapy in terms of drug efficiency. Of course, it is the most important issue for the afflicted persons, but there will be no new discoveries among us after this discussion.

Dr P.K. Das : We have to be aware of the respect due to an individual who comes forward. One suggests providing relief, while the concerned person is asking as well for status. Let us respect them. That is the most important thing. This can be discussed in private as well. If you start an organization to help others, or if you want to come forward to empower them by giving them a status, you are welcome. As an individual I appreciate it. In this case, treating a HIV patient is not an easy thing. As you said, the vomiting side-effect is not the only problem faced by the HIV patient.

Dr. Subramanian: He is not talking about the medicine that is why I am asking.

Ramapandian : You are there to meet other individuals. Maybe in the future, it will be possible to generate mutual interactions among positive people. That is what I am doing. I am trying to work on a level with other group members. Actually, a story about myself was given in a famous Tamil magazine. The post box number to contact me was also given. Most of the people responded to that article and through it they kept contact with me. Afterwards, I continued stories about people living with HIV/AIDS in the Tamil magazine called the "Evening News Today" in Chennai. Every Tuesday, there is one story about a positive people which appears. More than 25 stories have appeared in the past three months. I am basically a pharmacist and a paramedical person. I have all the clippings with me. If you want, I can send to anybody who wants. I have also counselled people living with HIV/AIDS. It involves basic home cure.

USA Raghavan : There are HIV positive people who have been thrown out of their houses. Do you have any place to accommodate them ? What sort of material support do you provide in your Tamil Nadu Positive People association ?

Ramapandian : Actually, when we are in touch with people thrown out of their houses, we refer them to the shelter of the Positive People's association. We have a network with other NGOs who provide services for employment, temporary shelters and school education. It has happened that some positive women came to see us for employment purposes.

USA Raghavan : In a country like India, it is very difficult doing all the work through the same NGO. Do you try to influence the government and other NGOs to work as partners, to influence and advocate the rights in all other services whenever you need. If yes, how do they react?

Ramapandian : There was an article talking about the government officers which came out in the press. The government officer then called me and told me that he would like to help positive people. But this way of approach may not help in the future. I am afraid that that kind of statement by the government officers would create some problems. I also approached the State Government Health Minister and he did not come for releasing the book. He said he had other political commitments.

Dr Subramanian : In your life story, you have said that your employers took your resignation when you were found HIV- positive. Did you get back your previous job or not?

Ramapandian : No, I have been thrown out. I am doing a new job in the field of HIV/AIDS. At the very moment, I did not react because I was in a helpless situation. I was not aware of my rights, nor did I understood what had happened to me. Today we would encourage and assist the individual, through the association, to take steps.

Dr Subramanian : Recently, I read a case in the newspaper about a seropositive person who filed a case against his employers who wanted to reject him. It was in Mumbai in the District High Court.

Ramapandian : The one you are talking about is a recent history. Mine was 6 years back. I was really in a difficult situation, having to face society and to talk with other people, even with my own friends and family members. I am in a position to talk here because I have been continuously interacting, encouraged to disseminate my feelings. Continuous encouragement to free talking has been given to me. That is the reason for me to be here among you. If at all the hospital where I was working were to be ready to take me again, I would not accept it. The past is difficult to forget.

Usha Raghavan : Let me answer this question. Ramapandian doesn't want to return to his previous place, because he has already been thrown out. Then, there is no reason for him to go back to the same place because he has got so many other things to do at present. Needless to think about the trauma of going back.

Dr Subramanian : The point is not to deliberate on his return. Ramapandian is courageous enough to come out, to speak, to organize and to live honourably. But you cannot expect the same situation for hundreds of people like him. He represents a particular case, he is strong enough and he has friends and he can survive. But there are many people who are simply thrown out and who do not have the same opportunity to rise up. I was thinking that if a person like Ramapandian approaches the high court, other employers would hesitate in the future to practise similar discrimination. It would generate a process.

Ramapandian : I am ready to fight. I discussed the matter with a lawyer, but he advised me that it would take a long time to get through. So I did not file a case against my employer.

Dr Abdoul Ahmide : We have to understand the feelings of the patients and their attitudes. Theoretically, the doctor should offer medical treatment to any patient. When a doctor offers a medical treatment to a HIV-positive person, it is always important to respect the doctor/patient relationship. Many doctors are doing this for the sake of publicity, specifically in the time of the epidemic : this should be avoided. We have to be clear that there are no drugs for AIDS in India at present. Even if you give 50 000 rupees per month and buy three drugs for anti-viral therapy, we cannot save the life of the patient, but the duration of one's existence may be prolonged for some months or years, a maximum of several years. We should remember that act before undertaking this kind of experiment on patients. We should also inform them about all kinds of side-effects during the time of experiment. Very often doctors do not get adequate information from such people who talk without knowing what they are talking about.

Speaking to the Gays in the city

B. Sekar, SWAMM, Chennai (Tamil Nadu)

Social and self-recognition

I am from an NGO, namely *Anbu Illam*, situated in Chennai. We have now formed Swamm - Social Welfare Association for Marginalized Men - and all the members are gays. We call ourselves gays because we feel different than other men, because we are more emotional and we like to be together either for sex or life. We have been working for three years for a very well-known NGO in Chennai called Community Action Network (CAN) which was one of the first NGOs in India to work with *ali-s* (transsexuals), prostitutes and gays.

Recently we felt the need for starting a community-based association dealing specially with the needs of the gay community in Chennai, and in Tamil Nadu for a further expansion programme.

We have broadly divided our activities into two basic segments :

Dealing with HIV/AIDS

The special thrust is towards HIV and AIDS in creating awareness, in educating the community in the ways of protective/safe sex. We are also providing health care and follow-up of the health care programmes with regard to the epidemic and STD infected persons.

Social upliftment of the community

The special thrust is towards the upliftment of the morale of the people of our community and instilling in them their sexuality. Our purpose is thereby to create a sense of dignity and self-respect which, due to Indian culture, are lacking. We want to broaden the social outlook towards the gay community. We hope to gain acceptance among society as such, and above all, we starve to come out of the vicious circle of self- marginalization

It is evident from surveys conducted by Swamm that we are considered as a highly marginalized group, and that most of us consider ourselves as a high-risk group. However, almost no NGOs have taken up work among us. It may be because of the same preconceived sociocultural and legal conditions existing throughout the country, insofar as homosexuality was still a criminal offence in India in 1997.

Our assumption is that it is with the realization of ourselves as being gay that we will be able to communicate more effectively among our group. The notion of identity is crucial for us. The community-based organization has set itself the task of serving, educating and caring for those who have been infected with the deadly virus.

However, we do not restrict our activities to our own small circle (which in fact is not so small), and I am working to create awareness among school children, awareness of HIV/AIDS and awareness of sexual exploitation. A long time back, I was a victim of this, and if my experience can be at all useful to other youth, my action will have a meaning.

Prevention in Chennai and establishing a network among gays

I am a homosexual and a HIV-positive person. In my organization, there are a few positive people and many gay people. We are doing counselling and distributing condoms to the gay community. I am a positive person because I was infected through homosexual activities. During my days in college, I did not believe that I would be infected through homosexual activities. When I became infected, I realized the truth and started to work for infected people. One should not blame only sex workers, who are high-risk group, but us, too. I go to the beach and find the gay people to distribute condoms. I regret to say that no one comes forward in public to say that he is infected or that he belongs to the gay community. I feel sorry for that because you cannot imagine, in fact, the number of married and well-established persons who ask for our services.

Homosexuals are not only in Chennai but everywhere in Tamil Nadu. Nowadays gays are coming from various towns in Tamil Nadu and through them the network is expanding. Homosexuals also belong to the high-risk group and are spreading HIV infection to their sexual partners. I created my organisation for the gay people. There are also many gay people outside of my organisation, some who do not feel themselves as a part of the gay community. In terms of vulnerability, I am afraid that they are more in danger because they are isolated and prevention messages do not reach them. I request those people to form a self-help group, or to come forward to support our organization.

At present we are distributing condoms at most of the pick-up points in the city. We act as a lobby in case of police harassment or in other trouble. People know that I am not afraid of speaking openly and frankly. Even if the law is against us, we are struggling to change it, for the sake of everybody, for the sake of human rights. Too many people use the pretext of the law and of discrimination to force children to enter into prostitution, by blackmailing them and threatening to inform the parents, the relatives or the police. Only if we join together can we enhance our position and status. People should welcome us because we want to make a clear distinction between us, the gays, and the child sex-abusers and paedophiles who at any time may approach innocent children. Underground networks are very frequent, more than anybody here can imagine in that assembly. We feel it is our duty to inform the general population.

Discussion

F. Bourdier : Actually four gay associations, including Swamm, involved in the field of HIV/AIDS prevention and care have emerged in Tamil Nadu : two in Chennai, one in Madurai and the other one is more like a part of a national network. A few years back, nobody could have thought about this. It is only a beginning, but a process has started. There are other gay associations all over the country which have existed for years in Mumbai and in Delhi. But these are mostly composed of upper-class persons, while Swamm is trying to bring together persons irrespective of their social background. Some are from rural areas, from slums, from poor and middle classes. It is a composite group in which the sole common denominator is to claim an identity that so far has been proscribed in India, even if this is contrary to what the common sense would advocate; and, homosexuality has existed in India from early times. Historical evidence, either in literature or historiography, prove it. However, I met some NGO leaders this year in Tamil Nadu who told me that there was no point of studying the sexual behaviour of homosexuals in India because there were none. Subsequently, there was no risk among men. They admitted, at the most, the potential existence of deviance from persons that were to be treated, but neither married men nor youngsters could claim a status of homosexuality.

K. Santosh : Again, it demonstrates that such a denial increases the vulnerability to infection, as well as decreasing the potential strategies for care.

Man respondent : I happened to read in the newspaper that homosexuals are using a special kind of condom and that it is available in India. Is this true ? I have heard that the condoms available in Europe for homosexual activity have an apple taste.

Usha Raghavan : Yes, it is true that they are using a special kind of condom which is not available in India. Here, one uses the *nirodh* condom instead. The apple flavoured condom is used for oral sex

Children, orphans and AIDS
Dr Manorama, CHESS, Chennai (Tamil Nadu)

Everybody knows that the first case of AIDS was reported in 1982 in the USA. Afterwards, it was estimated that paediatric AIDS would form 2% of all AIDS cases. Later, it was argued that infected children may increase and almost equal the heterosexual transmission rate. A few countries in Africa show figures with that tendency.

The topic I have chosen to present here is diagnosis, management and prevention in the family as a whole, especially in the setting of social destruction and poverty. Consequently, it is of interest to epidemiologists, sociologists, social workers, advocacy groups, social workers and policy planners, not to forget the medical fraternity.

AIDS has affected all segments of society, but the particular interest of our organization is the care and support of AIDS orphans, with whom we have been working for the past three years. Under AIDS orphans, we include infected children who have either been abandoned by their families or those who have become orphans due to death of their parents.

When coming to the problems of the AIDS orphans, parental support has to be discussed. Care centres have to be planned, insofar as there are none. Medical care has to be taken in a most serious way and their general education also has to be taken into consideration. In addition, the various infections which spread among them, either through drugs or sex, have to be considered. Children living with the virus have to be the first to be aware of their vulnerability and the potential risk of transmission which they carry.

Coming to the increasing number of AIDS orphans, the crucial point is reinsertion. Are their distant or close families really going to accept them in the future? A common feature is that whenever there is a positive child, he or she is immediately separated from the other children of the family. Marginalization, seclusion, and ultimately abandonment are the major problems, because if the family is not taking care of the child, who else is going to do it? Are we going to create more orphanages for infected children? That is definitely not the solution. That is why, through CHESS, we planning an alternative solution for infected children. We consider our structure as an intermediate and temporary one between rejection and re-integration, either in the same social milieu or in a new one.

There are a lot of constraints in the area of parental support. The parents are not able to give full support to their infected children. The seropositivity regularly results from the mother and/or father. If this is not the case, a lot of complications are created in the family, specifically between the parents. We have observed that among the children with whom we are dealing, the couples are frequently unstable : the mother is separated and sometimes the child is living with a single parent.

Such separation arises from the diagnosis of one of the parents : most of the men who are found positive when they come for testing immediately request us not to tell their wife or anyone about it. In that perspective, we have to take up counselling in a very serious way. The children happen to see their parents dying one after another. They don't know what to do in the future. What type of support can a single parent give? Likewise, we had an experience of a mother who was supporting her child, but never took the disease seriously. She was just trying to forget it. Only when the child showed a visible opportunistic infection would she come from Hyderabad (capital of the state of Andhra Pradesh), admit the child and take care of him. Once the child started speaking, she would say that she had an important marriage to attend, that she was the only person

left in the family and, by the way, she had to leave. After two months, she would again come back, bringing the child in a severe health condition. After repeating this a few times, the child left the world. Last year, similarly, a father had come with a small child whose mother had died two months earlier. The father did not know what to do with the child, did not know how to feed the child and how to bring it up. The child is now in our home and the father sometimes visits him.

So far we do not think anybody is prepared to accept the idea of adoption of AIDS orphans. There are compromises but none of them seem to offer an adequate solution. For instance, our organization was testing the idea of training and employing middle-aged women to keep at home the infected children. But if we are going to keep regular *aya-s*, it is difficult to know to which extent they will have an interest in taking care of a child with such a dreaded infection. Any voluntary organization has to face logistical and material problems like funds, legal issues of adoption and infant death. Funeral services are also rendered by our organisation. We spend about 10 000 rupees when a death occurs among the children for who we are caring.

The major issue in medical care is how to make doctors accept the positive patients for treatment ? We have observed that the first discrimination is found in the medical sector, and I am ashamed to say that recently we conducted a paediatric training programme at which one of our senior doctors asked about lachrymal and sweat transmission. Once divulged, such ignorance and misconception creates a lot of fear among the medical personnel. But, conversely, we have also to educate the public on the incidence of HIV infection through saliva.

Coming to the family settings, advocacy, moral support, the rights of the children have to be planned. Advocacy support for non-affected children for the prevention of transmission of HIV/AIDS should be thought of right to education, child health programmes, accommodation, transport and employment; prevention from other infectious disease should also be thought of. The positive child should be allowed to go to school. CHESS has been fighting for the past two years with school authorities in Chennai. But the government, as well as the corporation institutions, should overcome those problems, not a small organization like ours. But no parent will be there with the children in the schools. I do not know how the teachers will treat them. Instructions should be given to the *aya-s* caring for the infected children.

The development of a new environment in school raises some important points in terms of prevention and control of the infection in schools. Many of you may have encountered such problems. We have to teach the children at school to take care of their health and to wash their hands before and afterwards, just as we must teach the students about general precautions like not touching anyone's blood. We have to teach the children that if they find any bleeding wound, they have to call the teacher or somebody in charge of the institution. Keeping the school grounds clean and removing broken glasses and other objects should be also taken care of, because most of us know that the children carry blades to the school instead of pencil sharpeners. First aid kits should be available in schools. Wounds should be taken care of. The teachers need not be afraid of handling a bleeding child. The most important and single best method for the prevention of the transmission of infections is by cleaning and washing one's hands. Subsequently, the role of the school comes under the role of the teacher. The teacher becomes a potential care giver. When we talk of paediatric AIDS and its orphans, we have to make an intensive intervention with the school authorities. I really wonder when and how we will solve these problems. What is the role of the policy makers, NGOs teachers, parents' and teachers' association, students in the prevention of the disease ? Let us wait till day dawns, but not later.

Discussion

Karl Sequeira : In our centre, we have HIV-positive children and we are at present facing the problem of school admission. Parents of other children, if they come to know, will take their own children out of the school. In Bangalore, in the colony where I live, many of the families are well-educated and belong to the upper-middle class. When I asked about the admission of a positive child in the school where their children are studying, they replied immediately without any hesitation that they would take their children out of the school, even though they know that the risk of transmission is very low. Actually, we do not have any school for the admission of our children who are HIV positive.

Man respondent : I also happened to see a child of eleven years who was infected at birth. Could you please give more details about the potential spread of HIV through saliva?

Dr Manorama : In general, the children do not live more than five years, but we have some children of eight or nine years who are still alive. Regarding the modes of transmission, HIV passes through saliva, but not through sweat or tears. This has been recently proved in an international scientific review, so there is no doubt anymore about this. We have to explain to the medical fraternity of high-risk exposure where large volumes of blood being handled. And I would like to bring to your notice a work which was done on the overall risk calculated at 31% through careful exposure. Regarding the problems in medical care, the care of positive children and the care of doctors and nurses are to be considered. How many precautions can really be followed regarding the disposable materials which are available in government hospitals or which can be bought by doctors in private sector? The type of articles for sterilization and insulation to be used are very expensive. Separate training for doctors is to be given on how to take care of them. At the same time, I think of the quacks who are making huge sums of money because the government is spending crores and crores of rupees on saying that there is no treatment for AIDS. One simple advertisement in the newspaper which costs around 15 000 rupees, may lead the people to believe that there is a medicine to cure AIDS and they need not bother about other preventive measures. There is a *vaidyar* (*ayurvedic* physician) like this in Cochin, Kerala. He takes 9 000 rupees for a treatment made out of simples leaves and other products which he is keeping secret. Coming again to medical care, when they come to the paediatric department for testing and for the treatment, all children must have the chance to receive treatment. Because there may be an alternative drug therapy and alternative method of management. Biomedical research has to be expanded. Clinical trials should also be planned. Adequate funding should be allotted for the treatment, training and support of clinics to accomplish the above and to provide a better medical-care environment. We have to develop sophisticated and decentralised health control research centres at various places.

An experience of residential care in new Delhi

Joe Rocha, Sahara organization, New Delhi

My colleagues, Francis De Souza, Momoi Tonsing, and I come from Sahara house which is a centre for residential care and rehabilitation. First of all, my friends and I want to thank Frédéric Bourdier for the wonderful hospitality that he has shown us and the opportunity that he has given us to share our experiences with you.

Let me tell you briefly about myself. I was a drug addict and an alcoholic. When I was seven years old, I became a drunkard. When I was 16 years old, I was a full-fledged drug addict. I could not stop drinking. I literally took drugs from the time that I started to work in the morning until I went to bed. I am not exaggerating. When I look at myself today, I am quite ashamed of it.

People who loved and took care for me did not help me. I left my house when I was a drug addict. Every day, I made my mother cry in order to get money for drinks. Then she went to Goa and she died there. I got the news when she was sick. I wanted to apologise for my activities which caused her pain. But she left me no chance to do so.

By chance, I went to Sahara house. I met the person who was running the house, Neil Seloh, as I was desperate to go back to Bombay. In fact I literally begged people to give me some money for the ticket to go back, but in vain.

I come now from the Sahara house where sixty people are living. All of us love each other. We understand each other. I have a wonderful life in the same house where three children are brought up. Everyone in the house takes an active part. After six months in Sahara house, I felt that I had been leading a calm life. Now, I fully understand real life. I have come to understand the meaning of responsibility, discipline, the worth of loving each other and the value of life.

I don't drink anymore. Living in Sahara, as I have already said, there are drug addicts, alcoholics, chemically imbalanced people and HIV/AIDS patients. My friend Zia in the care department is taking care and giving special attention to me. Once, an HIV patient told me that he was going to die. At that time, I thought that God disposes the end of one's life and there is also a fact that everyone dies one day. A lot of people say that they have achieved this or that. But when a person is born he comes to the world with nothing and when he dies, he takes away nothing. So it is only his achievements for himself or others that count.

Hence, one leaves the world, leaving one's achievements behind. When I thought about what I was going to leave behind me as achievements. I came up with nothing. What do I have to leave behind in this world ? I decided to render services, whether it is right or wrong.

Today the disease of HIV/AIDS is a burning problem throughout the world. I decided to serve the affected community. I am part of that society. I don't want any profession. I don't want any designation. I want to serve and love. There are people in this world who are always saying "I did this because he did that ; she did that because he said that or she said that." I want to live a worthy life, that is satisfying and fulfilling the hearts of others.

As a result, I began to go to the hospital to see the patients who had full-blown AIDS. I sat beside them and took care of them. I looked at the AIDS patients and saw that they were terribly ill-treated.

I admire the gentleman who spoke about his status (Ramapandian) and who had courage and the guts to say that he is positive. I would like to meet AIDS patients or HIV-positive people. I would sit with them day and night. I don't care whether they have full-blown AIDS or not. If someone has done this for me, why can't I do the same for others? That is what I am doing. But I am trying to do it in my own way and trying to be grateful to Sahara and to Neil Saloh.

I was an addict. I was an alcoholic and today I know myself better. If I did not happen to meet Neil Saloh, I might have met death on the roadside. Today I know myself better. I still want to know myself until the last day of my life. It is a kind of learning process. For this, I thank Mr. Neil Saloh and I also thank each and every one of you here and especially Mr. Frédéric Bourdier for having given me a chance to share my experience with you and to inform you of the existence of Sahara house. Thank you. If you want to ask me any question about Sahara you are most welcome.

Discussion

Usha Raghavan : I have heard much about Sahara. Is there any possibility for the people from the South to establish connections there? We would like to know how you are working together in Sahara. That is what is most important regarding the networking.

Joe Rocha We are residential. All sisters who are concerned and willing to share, can do so. Some of us have worked in the slums, some in the information centre. Whatever information you want, you may ask. We can definitely keep in touch, correspond and exchange information. We don't know everything and we don't forget that you and other NGOs can help us also. We can always share. Actually, I would be very glad if all the NGOs would give me their addresses so that we can keep in touch, because we really need to join together to fight against HIV/AIDS

Usha Raghavan : I don't want this seminar to be like any other workshop because this present seminar has social and psycho-social scientific aspects which should not erase the emotional dimension. I ask you this question because everybody usually says that they will keep in touch after a workshop, but it never happens. I don't want, and I don't think, that this one will be like that. That is the main reason why I put forward the question. Literally, we are ready to give all the support and other things which we have from our side in Tamil Nadu. At the same time, the sharing and conveying of news, information, announcements is crucial. We are looking forward to a reciprocity.

Joe Rocha : It will happen, don't worry. We have certain people in the administration mainly involved in corresponding and keeping in touch.

F. Bourdier : Last evening, when we spoke together in your room, you told me about your relations with the biomedical sector in Delhi. Can you say a few words about the quality of your relation with hospitals ?

Joe Rocha : In the beginning, we had a lot of problems with the All-India Institute of Medical Sciences (AIIMS) in New Delhi and with the Suthar Gang hospital. It is really a tragic fact that the doctors were not willing to touch an HIV patient. We took a full-blown patient there, and the doctors refused to take him. We took him to Suthar Gang, they refused to take him as well, and finally he died. But we called the reporters from the *Hindustan Times* and the *Pioneer* (two daily

newspapers) and they wrote about it in their columns. Today, we can go to AIIMS and Suthar Gang and they put out the red carpet for us, because they know that we can react and inform the public opinion. I can sit in their offices at present, and I am ready to do something for such patients or such slum dwellers if their rights are not recognized. At Sahara, we don't advertise but in case of problems are encountered, we are ready to make a noise about the affair if it can be of help to others. I want to call the human rights activists, reporters, and I want to stand on dams and in parks to shout about what is happening all around me and around us. Because it is our people, in our state, in our country. It is us. Indians. We are fighting for ourselves. We are not fighting for somebody who is outside our country. That is what we have to do, we have to get what we want to get. We don't want to wait for people to come to us. If they are not willing to give us what is ours, we have to go to them to get it.

F. Bourdier : Dr.Abdoul Hamide, you are in touch with people living with HIV/AIDS in Pondicherry. Can you give us a few words regarding your activity ?

Dr Abdoul Hamide : The public hospital in Pondicherry has been facing the epidemic of HIV/AIDS. The first patient with HIV was encountered in 1989, and since then the number of patients has been increasing. So we felt the need to start an HIV clinic. Earlier, we had an AIDS care group. We had doctors from the STD clinic in this unit. The care group was active in dealing with the problems of blood transfusion and related problems of HIV transmission. But we felt the need of starting an HIV clinic in our department, the department of medicine. In March 1997, we started a clinic which runs one day per week, on Wednesday afternoon. It caters to the patients who are referred from the other departments, from the blood bank, as well as those who are voluntarily coming for HIV counselling. If any donor has been found to be positive, they send him to us for counselling. Most of the patients are from other departments and 80% of the patients from our own department are patients who are coming to our out-patient service, or had already been admitted once or twice in other wards. The rest of the patients have been referred from the other departments. Mostly we do post-test counselling. Very few patients have come for pre-test counselling. So far, we have seen about forty patients. Since March 1997, HIV-positive persons and full-blown AIDS patients come to our clinic. They are mostly in the age group of 20-35 years. Only five are females out of forty persons, and we have noticed that the people are coming essentially from Trichy, South Arcot and Salem districts of Tamil Nadu. Though we are situated in Pondicherry, our hospital attends to patients from most of Tamil Nadu. Most of the Pondicherrian people go to the Pondicherry AIDS cell, and much overlap is avoided. The patients are mostly infected with tuberculosis, insofar as the main secondary infection is tuberculosis, chest TB or extra plummetoid TB. We are mainly involved in counselling these patients regarding what type of work they do and their sexuality. We determine whether they have any awareness regarding STD/AIDS. We have found that only 40 to 45% of the people we aware of STDs, and half of them were not aware of the HIV infection. Among the STD patients, the people aware of STDs were hardly aware of HIV and related problems. We have a psychiatrist who takes care of the problem. Once the patients have received counselling, they go across to the psychiatric office where one deals with problems like depression. The profession which is the most informed regarding awareness is the truck drivers, followed by other professionals like businessmen and employees in the government sector. Although they are lesser in number and our experience is of very short duration, we cannot generalize. We expect to continue and improve the work and we want to belong to a network dealing with care. We cannot do everything alone. Starting a process, we want to continue to know about the patients who are sent back into society. One should take care of them, not only by allowing them to sit in the HIV clinic itself and consider it as a mere drudgery. So far, we have not been able to provide real counselling or to give them proper

psychological care. We try to give them the courage to live with the disease. We have nothing else to offer except attending to TB and other secondary infections. So we want to have the care continue. The aim is not to keep the patients in a clinic but to put them in society, and to be sure that they should be attended to properly. We should like to have any suggestions from those who can to help us in this respect.

Dr Shukla : I would like to know about the total number of patients you have seen. Can you give us a rough idea of percentage of TB in the HIV-positive patients ?

Dr Abdoul Hamide : Out of 45 patients whom we have had, only 40% of them are suffering from an ailment other than TB, the remaining 60% have TB.

Dr Shukla : You said you would like to have some suggestions. I can tell you what we are doing with HIV-positive patients at the TB centre in Nashik. We send social workers to our patients in order find out about their problems, how they live and what they need. We find that counselling is important for them. One should have a way of keeping in contact through a social worker visiting the patients at home and, as you said, a unit for continuing care.

F. Bourdier : Dr Gaikwad, from a town in Madhya Pradesh, can say a few words on that issue.

Dr Gaikwad : Since I was a student in second year MBBS, we have been taking care of many AIDS patients and HIV-positive cases. We know about the problems with the government, the lack of out-patient departments (where timings are very restricted). Furthermore, there are neither proper premises available nor privacy where the patients can talk with the doctor. There is not an adequate staff. Only a doctor who is not at all trained in counselling the patients. Doctors and paramedical staff have their own prejudices. They have their preconceived ideas regarding the HIV-positive patients. In such situations, at present, the government hospitals are not working properly. It is either the doctor or a social worker - with only a masters degree and not a proper attitude to work with patients - who are providing counselling. Such social workers do sit in the clinics, but they are not of much help to the patients. For the sake of duty, for the sake of a job, they just attend the STD clinics and keep on registering patients, just by filling up the proforma. They are definitely not ready to talk with HIV-positive and AIDS patients. In other hospital wards, we are facing the same problems : the nurses are not ready to touch the patients, to treat the patients. We have to repeatedly tell them and motivated them to take care of the patients. These are the problems we have in the government institutes or anywhere else. The in-charge who is looking after all this affair should be sympathetic to the patients; if he himself is not ready to co-operate or be sympathetic with or have a good attitude towards the patients, the staff under him will also develop the same attitude. If the in-charge has the “ know-how ”, then the staff under him is also gradually compelled, forced or motivated to adopt a good attitude towards the patients. It will take a long time, but it will be.

David Thiagarajan : In Rajaji hospital, the STD department people take over the responsibility of dealing with the HIV-positive cases. Dr Ganesan is there and all the cases are going to the STD department. They refuse nobody.

F. Bourdier : The quality of the relation between one person and another one is the key to the system. Let us not speak of the quantity (how many people have received counselling per day), but about the social relationship established between people who tried to understand each other. It is more important.

Dr P.K. Das : Maybe one thing that I could suggest is finding out person among the HIV-positive people who is motivated to help the others. He would be in position to create a kind of framework and set up a self-help group of HIV patients. Once the self-help group is set up, the motivation of the person who is positive to help the other HIV patients will be tremendous ; and you can use that strategy. The tool born in the machine is a very powerful help.

Dr Abdoul Hamide : I have thought of the problem, but the patients are coming from distant places, and most of them are living in different places. They are not in the same place and the more a layperson knows the stigma, the more he does not want to reveal the status. That is the main drawback, that is the barrier of any project. I have thought of that, and even wanted to ask Ramapandian for more details about how he managed to form his group and under which conditions, and how we can do that ? Maybe there is someone other than Ramapandian who is ready to answer these questions ?

Dr. Bobby Zachariah : I come from M.N. Nagar in Maharashtra state. It is only three hours journey from where Dr. Gaikwad is working. We started working on the issue of HIV/AIDS in 1992, when we found one patient in our hospital. It is a 170-bed hospital : in 1992 we found two cases and in 1993 we found around six or seven cases. In 1994 there were fifteen cases. Now we find two to ten cases every week in our hospital and we are caring for HIV-positive people in our hospital without discrimination. They are admitted along with the general patients. We had several problems with our staff, in the sense that the doctors weren't willing to treat the HIV patients. Consequently the staff were not co-operative. How was it sorted out ? We started with staff education and then persuaded doctors and paramedicals to change their behaviour. First of all, they could not avoid and reject a patient. When the patients started coming back to the hospital again and again with various diseases, we realized they were accepted, otherwise they would not have come back. When the doctors suspect that there may be some problems of immunity, we do a test with pre- and pro-test counselling. Once the patient has been found to be positive, he is encouraged to keep in touch with the hospital staff, and whenever he has an uncertainty we have a support group every month so that all the positive people can come and share their problems. The group basically consists of positive people, family of positive people and a few persons from our staff. Everybody can question the others. One of our doctors and nurses are ready to deal with the medical problems which are discussed. We follow them back to the community to teach them home care. The positive persons, in fact, come from villages and they are not able to bear the cost of travels and the medical bills. So we go to their houses and give them basic medical and home care. We also visit the homes nearby. What is important is that the community doesn't start discriminating against the individuals who are infected . The community starts taking care of the sufferers. This is what we perceive as an improvement, as a social prevention that concerns everybody. The whole community is changing its behaviour.

F. Bourdier : Another question about the bringing together of people living with HIV/AIDS of which you speak. Was it a decision of your hospital, or of the people themselves to attend a gathering ? It seems that everything is going on well. Were there any difficulties at the initial stage of implementation ? What are the eventual drawbacks you have experienced ?

Dr. Bobby Zacharia : I don't know. I joined the hospital one and half years back and don't know exactly how the idea was initiated. But there are similar meetings happening in other places like Mumbai. Prohibition to talk on HIV/AIDS is slowly disappearing. The concept of *support group* is determinant. It helps the person to be followed, to avoid self-exclusion and to manage to get out of social isolation. The positive aspect happening at present is to encourage the positive people to bring their families, because they are the ones to have the doubts. The stigma will be removed when their attitudes are taken into consideration.

F. Bourdier : Ramapandian, Would you reply to what Dr.Abdoul Hamide asked you. What do you suggest to him.

Ramapandian : I am basically a counsellor working in the NGOs. So I have had the opportunity to meet a lot of positive people. It was usual for me to interact continuously with positive persons any time they needed something, especially for the treatment and for employment problems. I had regular contact with all the positive people. It provided me with a good interaction among them and I gained confidence among them. I speak with them individually and we share experiences. It was easy to understand the respected talks taken as guru's words⁶. For, once the patients had come to the NGOs where I was working, they behaved as if they would have come to talk to a guru. The people started speaking with each other, then they wanted to have more and more meetings and wanted to participate more, to be more involved in the process. That is how and why I, with other HIV positive friends, started the positive network. Initially, it was very difficult. Some persons were reluctant and only a few people turned out for the meeting because if you come, someone will come to know your status. You would be afraid that your friends would come, that someone who knows you already might join the group. Such were some of the reactions and feelings of the positive people. So we slowly build up the rapport and gain confidence and talk altogether. Continuous interaction needs a lot of work. It has been more than four years that I have been working in this area. It is not a gentle task to form groups, but once they are formed it is becomes easier.

Dr Shukla : Because there is no treatment for HIV, there is a fast burn out of interest and the people become emotionally weary. This has led to a difficult job. Only a few people can manage to continue to work in the same place for more than five years to seven years.

⁶ A guru is a charismatic spiritual leader, a person who have the knowledge and who transmit it to the others.

Social Aspects of HIV and AIDS in Goa

Mary Finch, Positive People, Panjeem (Goa)

To most Goan people, the epidemic of AIDS has seemed to be a comfortably distant threat - a disease affecting the outcasts of society such as commercial sex workers, their clients and drug users. In this presentation we will show how the public's response to HIV/AIDS in Goa has affected those who are HIV-positive, and what efforts are being made by our organization to change the negative social response and make life better for those who are HIV-positive.

It has been suggested that when a person is first diagnosed as HIV-positive, he or she has to deal with both psychological and social problems. In addition to experiencing feelings of despair and depression, he or she may lose social contacts - including family support -, as well as losing employment and encountering other social problems.

In fact, Positive People has seen these problems many times through our clients. The founder of the organization, Dominic d'Souza, experienced such problems at first hand. When he was initially diagnosed as HIV-positive in 1989, he was treated very badly by Goan authorities. Dominic could think of no reason why police would want to see him, but he went along. At the police station he was escorted to one of Goa's government hospitals. When being interviewed, he saw the words "HIV-positive" on his medical notes. Everything suddenly became clear to him and he realized why he was being treated in this way.

Dominic was held under police protection at a shut-down TB hospital in Goa for several weeks. Food was given to him through a window, and doctors did not enter his rooms, only standing outside to ask how he was.

The Goan authorities had never faced treating a HIV-positive person before. The first HIV-positive person diagnosed in Goa was a foreign tourist who was immediately sent back to his own country. The second was a migrant worker from Kerala, and the government was able to send him immediately back to his own state. Thus, the Goan authorities did not know what to do with Dominic.

Dominic's isolation evoked much outcry from his family and friends. His mother filed a petition. An interim order was passed for his release, and Dominic was allowed to go home. The government acknowledged that discrimination and stigmatization of HIV-positive people undermined human rights, and since Dominic's release in 1989 no HIV-positive person has been isolated in Goa.

Dominic went on to lose his job because of his HIV-positive diagnosis, due to his employer's ignorance and prejudices about the disease. He decided that something should be done to raise public awareness and understanding in Goa regarding the true facts behind HIV and AIDS. He decided to form an organization with this aim, which is how Positive People was formed. Dominic died in 1992, but Positive People continued and is now the oldest and most established NGO in Goa dealing with HIV and AIDS. In fact, there is only one other, which Positive People now oversees and supports. Today, over 1340 cases have been identified as HIV-positive in Goa. Goa has the sixth highest rate of identified sero-positivity of all Indian states, according to Goa statistics.

Our main aims are: (1) to raise public awareness about the epidemic and (2) to support those who are HIV-positive in Goa. In order to fulfil these aims, several projects have been developed arising from social needs which have been identified in Goa. These projects include:

1. Beach Boys Project (coastal belt) ;
2. Truck drivers - health education and condom distribution ;
3. Construction workers - health education ;
4. Commercial sex workers - health education ;
5. Schools and colleges - health education ;
6. Women's groups - health education ;

7. Supporting those living with HIV and AIDS ;
8. Counselling in STD clinics (including pre/post-test counselling) ;
9. Industrial workers - health education.

We cannot describe all of these projects in detail at the conference. If you wish to know more, please come and speak to us. Also, leaflets are available for anyone who is interested. We will instead describe one project to show how Positive People tries to confront social problems in a practical way.

The Beach Boy Project arose along the coastal belt of Goa where hotel workers, shack owners and the community are all educated by staff from Positive People about STDs and HIV. The goal of the project is to prevent the spread of HIV in these areas through encouraging maximum community participation.

As a result of meetings and teaching sessions, members of the local communities have gradually come forward to donate money to Positive People, to volunteer to teach others in their area about HIV and AIDS and to help support those who are HIV-positive in their community. As a result, community networks have started to form so that Positive People can gradually move from a teaching role to a more supportive and facilitative role in some of the beach communities. This change, although a slow one, is very encouraging.

In order to achieve this change, creative work has been done to treat as much of the community in the coastal region as possible. Activities such as organizing public meetings, distributing a local news letter, giving out information leaflets about HIV/AIDS, offering condoms to those who would like to use them, and trying to get as many letters and articles as possible about HIV and AIDS published in Goa's newspaper have all helped to raise the profile of the subject of HIV and AIDS in these areas.

Positive People tries to be as creative as possible in doing its work, but there are many obstacles in our path. One challenge for our staff is that Goa has a strong religious and cultural background. The 1981 Census shows religious belief to be divided in the following proportions amongst the Goan population:

Hindu	64.2%
Christian	31.4%
Muslim	4.1%
Other	8.3%

These statistics will not have changed significantly in recent years. As in most parts of India, most people are very orthodox in their religious views. This can make it difficult for staff when trying to promote discussion about many issues relevant to HIV and AIDS, such as sexuality, condom use, and the education of commercial sex workers. HIV and AIDS therefore remain a taboo subject for many Goan people, meaning that Positive People has to struggle very hard to achieve its goals.

Many schools and colleges oppose the discussion of sexuality with pupils and prevent project workers from educating young people, who are possibly most at risk from contracting the HIV virus in the future. Another problem we face is that commercial sex workers, who have until recently been based in a area called Baina, have become scattered around Goa as a result of attempts by the government to prevent people from using their services. As a result of this, sex workers are much harder to contact, and both teaching them and distributing condoms to them have become much more difficult.

Because of Goan society's attitudes and beliefs related to HIV and AIDS, when a person is diagnosed as HIV-positive, invariably his or her response is to tell nobody and to suffer alone. Those who do tell their families have reported that their families often reject them and feel unable to deal with the news or support them.

The social stigma attached to HIV and AIDS is therefore extremely powerful and many of our clients do not wish to share the fact of their diagnosis even with their closest friends. Positive People aims to help these people come to terms with their diagnosis through counselling and support, and to begin to break the barriers of social isolation which they experience.

It is hoped that in the future more and more Goan people will understand the facts behind HIV and AIDS so that the spread of HIV will be halted and the social stigma behind the epidemic will be removed. There are some longer-term projects which Positive People hope to carry out. One is the establishment of a hospice in Goa for AIDS sufferers. At present our clients have to be taken to Bangalore for such care. We are beginning to raise support for this venture.

We would also like to look into improving the training of both medical and nursing students in Goa through liaison with colleges. Another idea for the future is to explore the possibility of creating a specialist HIV nursing role within Goa. A nurse undertaking this role could act as a link for clients between hospital and home. Such a role already exists in many countries around the world and has been of great value in improving both preventive work and the care of HIV-positive people.

We also hope to improve our counselling work, building better links with both public and private hospitals and doctors to maximize the number of referrals we receive. Very recently the AIDS cell deputy health secretary director invited Positive People to man a counselling centre in Goa's main hospital. so that links between the (DHS) and Positive People have become more established. We also hope to improve and develop links with other organizations in Goa, around India and world-wide. Positive People therefore has many serious challenges to face in the future. We hope that through creative thinking and careful planing we can face these issues and deal with them, and achieve our goals in Goa in the near future.

In relation to funding, because Positive People has been developing new plans and projects - for example the setting up of a hospice in Goa -, there is a need for donations as our current funding will not cover the costs of this new work. We would be very pleased to hear from anybody who might be able to help in sponsoring our work.

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Discussion

F. Bourdier : Does your association, Positive People, have any link with other NGOs outside the state ? What is the present situation regarding the laws implemented in Goa, widely known to be inflexible in terms of legal aspects related to HIV/AIDS ?

Dr Prabhu : It is now more relaxed. People who have been tested positive are not isolated and they are not discriminated against. At present, people don't reveal their status and if they do, they are less discriminated against than a few years back.

F. Bourdier : How did the change take place ? Was it due to any lobbying by legal organizations ? Was there any change in the law ?

Dr Prabhu : The major changes were made by the government when Dominic d'Souza was positive. He went to the schools and explained what had happened to him. He wrote down as well all the problems he faced with the government. He came out into the public.

Ramkumar : You have said that HIV-positive persons are no longer isolated. But when we look into the medical and nursing aspect, it is rather the contrary. The ignorance of the medical staff when they have to handle HIV patients shows not only inability as a general trend, but fear and repulsion as well.

Mary Finch : If I had longer to speak, I could identify many more details. For instance, a woman was forced to be isolated in a legal sense. She was very isolated in a physical sense : she didn't have visitors, and nursing and medical staff would avoid going to her room. She was physically separated from the community. This is what I was saying : we need a lot of work on training nursing and medical staff, we need to work to operate a change in their attitudes, insofar as they attempt to avoid going to the room of the patients and behave differently with them.

Ramkumar : There is another dimension. Actually in India, the AIDS epidemic is considered to be a medical problem rather than a sociological problem. Doctors adopt a very rigid position.

F. Bourdier : The fact that some doctors, administrators, epidemiologists are attending the seminar which deals with social aspects of the epidemic tends to prove the contrary. Some doctors are flexible in their approach, sometimes much more than some so-called social scientists who adopt a very positivist and mechanistic approach to research.

Usha Raghavan : Regarding the networking of positive people, we are intensifying the link between the Tamil Nadu positive people network and the Indian network of positive people. The government is encouraging every initiative and simultaneously is continuing experimental care approaches (community, family care and support). We are in touch with quite a lot of people from different agencies and professions (including the medical sector) and the government is ready to render help to any organization working in that field. But to improve our services, we do need the information from you. We also want to know about the feed-back of the projects to which we provide support : either from any hospital, any TB sanatorium, or from any NGOs and charitable organization. We can only improve our services and design a proper agenda if there is a constant evaluation of your experiences. Again, we need information to keep on both sides and research has to be part of a constant evaluation process.

Man respondent : I used to wonder why there was such a great interest in public health. Will it be a long-term process or is it a fashionable area to deal with? In fact, I wonder whether you have conducted any study regarding discrimination or isolation for further implementation or did you make any survey, because a law already exists in Goa.

Dr Shukla : I would like to confirm that Goa is the only state in the country which has got a special act for AIDS patients. The act legalizes, in a sense, discrimination and arbitrariness. It is a violation of human rights. Such a law has been widely criticized but it still exists.

David Thiagarajan : Not only the act is existing, but also the judgements. The pronouncement is that natural justice has to be followed. Whatever it may be, the isolation has been justified. Is isolation always non-discriminatory? And what about the judgement which is validating it? One has to remember that at the beginning of the epidemic, the infected persons were violently rejected by everybody, some were even killed by their relatives. It has happened in Tamil Nadu still recently. Some persons have interpreted the Goan law as a protective law. But according to the 1989 judgement, an infected person must be cared for before being sent out or before being isolated. The act recognizes the right to be treated.

Usha Raghavan : Anand Grover, a lawyer and activist from Mumbai, fought against the law which has been removed. He made an issue of it and said that it was not going to be implemented for long.

Dr Prabhu : The situation has changed at present in Goa. And that is where we, as an organization, have intervened. Whenever a person is stigmatized, we have to be with that person, we have to be present to help him to raise the problem in the family, as well as in the community. What we do in our hospital is that as soon as we find the person to be positive, we tell him the information and we encourage him to share this information which weighs upon him. We don't compel anyone: maybe he will not agree in the beginning, but we keep on counselling him. We tell him over the period of time that he needs to disclose the information because he may be sick within a few years. In that perspective, that nobody should keep the information only for himself, the person is encouraged to share it in his social environment. He may sometimes go and share the information by himself. Other infected persons will insist that we come to their family and speak with their parents. Some prefer to disclose the information themselves, and some need an outsider to be with them during this crucial moment. In the Positive People association, we adjust with different methods, there is no miraculous formula. Later, there is the question of social stigma. In many cases, we found that the community wants to throw out the infected persons. What we do is that we go to nearby homes, we talk to the people and try to convince them that this is not a health problem which can be cured and that the role of the community is to take care and, more important, to provide affection to the person. We are saying that their psyche improves as a result of this. Generally it works: most of the time community members change their attitudes and feelings. It is a question of social collective dynamics.

F. Bourdier : What about isolation at the hospital level?

Dr Prabhu : The AIDS patients who are admitted in the hospital are still, in many places, isolated. They are kept in isolation wards. The reason given by the administration when we try to convince them in various ways is that they don't have the facilities to protect their staff from HIV/AIDS infection. They do not have enough gloves, enough disposable syringes and so on. Most of the time, it is a pretext. It does not reflect the reality.

David Thiagarajan : Not always, in Madurai where there are a lot of cases, most of the hospitals don't isolate any patient. There is no special ward for AIDS persons. Like this, in many private and public hospitals, the situation is changing. The negative emotional aspect of isolation precautions is the same for all diseases. It is not only with HIV-infected persons. Isolation is never recommended.

Dr P.K. Das : Isolation is, *de facto*, recommended. That is why AIDS got around seven crores of rupees for wards for AIDS patients. There is a separate ward for AIDS patients at the All-India Institute of Medical Sciences in New Delhi. And that is one of the best medical institutions in India. Such isolated wards were also existing in Chennai a couple of years back, but they were removed due to strong lobbies.

Viswa Deepak : Any patient should be admitted in each and every hospital within the existing system. That is the situation that we have to create and we have to work towards that idealistic situation. The doctors may not be excused because they don't have any equipment or any disposable materials. They have to learn to treat any patient without knowing his status. Doctors are treating many people in spite of knowing the HIV status. In the future, they have to adopt non-discriminatory rules of protection for themselves and for the patients as well.

K. Santosh : The doctors have to change, to learn and to adopt new practices. Violence is too often a part of the treatment. Isolation reinforces the act of violence. To avoid discrimination, there is no other solution but to be treated along with the other patients. But that is not all. Ironically, isolation is strengthened when the AIDS epidemic is the object of a celebration, particularly on World AIDS Day in India.

David Thiagarajan : Recently in Pondicherry, three sex workers were isolated and were put in a separate jail following the magistrate's court decision. Usha can explain in detail because she was the one who took action to retrieve the three girls.

S. Usha : Three sex workers in Pondicherry were compelled to take tests for HIV. Once they were tested positive, they were put in an isolated cell and booked on a non-bailable charge for one year. I came and traced the three girls, along with the consultation of a doctor. The director of the Pondicherry AIDS cell, Dr Venkatesvaralou, also intervened in this regard and together we obtained the release of the three girls.

Dr S. Subramanian : Three months back, a familiar Deputy Inspector General, who has links with the AIDS Cell in Chennai, arrested 15 commercial sex workers in Tamil Nadu. He sent them for a blood test and the results were openly published in the newspapers. How does TNSACS react to this ? What steps did you take ? They openly told the names and ages of the persons.

Usha Raghavan : The question can be asked of the project director, but I can't reply to that.

Dr Abdoul Hamide : One more problem is that in most of the cases related to jail surveys, there is a ban. Due to the lack of social services, there is difficulty in having access to the information. Jail inmates, especially prostitutes arrested under the Immoral Traffic Act, are not in a secure position to claim their rights, nor are they aware that testing is not compulsory.

Usha Raghavan : When we make tests at the sentinel surveillance centres, it is not compulsory. Testing has been done in the prison under the sentinel surveillance designation, but it has not been systematic.

Man respondent : All the tests were conducted for the purpose of contagiousness. HIV is not contagious disease. The judges refer the case to the medical personnel to validate the contagiousness. It is not particularly mentioned to check them. No public health act says AIDS patients should be isolated. But if any health hazards or contagious disease prevail, they may be isolated. The problem therefore is due to the lack of knowledge, AIDS is perceived as something potentially contagious. Many doctors are still under the impression that it is. You may easily imagine that police officers, judicial officers are more under the impression than doctors that it is a contagious disease !

David Thiagarajan : In that case, judges have to be educated first. Some NGOs should propose them as a target group and make an intervention programme with them.

Usha Raghavan : Intervention programmes by NGOs are not needed at all for that purpose. The government is already doing that. But there is regular news of women who have been booked under the Immoral Traffic Act, and then screened for HIV. There is a non-bailable charge for this.

Dr Jaysankar : In the centre of Pondicherry, there is an area called Kan doctor Thottam (the land where was living a doctor). It is a well-known area for cheap prostitution. Five ladies were arrested because they didn't give enough money to the police. Afterwards, they were forced to be screened.

Helping with the people living with HIV and AIDS

Karl Sequeira & Nathalie Battais, Freedom Foundation, Bangalore (Karnataka)

My name is Karl Sequeira and I run an organization called Freedom Foundation in Bangalore, Karnataka. I want to talk about a patient whose name was Pandu. He came to Freedom Foundation nine months ago. He came because he was tested as positive. He didn't know where he could stay because he had no house. When he introduced himself, he had had no food for a couple of days because he had to run away from home.. He was entering the full-blown stage of the disease. He had no place to go

We got in contact with his family, upon which Pandu went off to his home for one month. Then he came back to Freedom Foundation. He was really in a bad state. He could not walk, having full-blown AIDS. He came to see us and told us that he came directly from his house which was somewhere around sixty kilometres from Bangalore. He had walked all that way to Freedom Foundation because he could not stay in his native place. His family had taken him back and locked him up. His parents would not give him any food to eat, as they did not want him to eat from the same plate as the rest of the family members. This was the situation, despite the fact that we had counselled them. Pandu somehow managed to escape and came back to our centre. He died three days before this conference. The only thing he had was that he died in Freedom Foundation with care, with dignity and surrounded by the love of about twenty-five patients who are also positive and staying with us.

Freedom Foundation originally started as a “Drug and Alcohol Treatment Centre” back in 1992. We do have in-patient facilities for drug and alcohol patients. At any given time we have about forty patients who are receiving treatment. The drug and alcohol abuse de-addictions generally take four months. In 1992, we started getting people who were not only drug and alcohol dependent, but also HIV-positive. Among these people who are positive and who also have a dependency problem, two of them did not have any place to stay because they had been thrown out of their house, either because of their dependency problem or because of their HIV positive status. The problem for us is to find a place for these patients to live .

Most of the people who have reached us had no income. We tried searching all over India but we could not find a place which would accept them. Finally, we decided to start our own home. That is how we created “Freedom Foundation” drug and alcohol treatment centre in January of this year 1997. We have taken 25 patients - 12 male and 13 female patients. Our centre was quite often full in spite of an acute need for more facilities. But initially, Freedom Foundation decided to start this in-patient facility for child patients because of the rejection these HIV persons face from their homes.

We take only patients who have been thrown out of their homes, who have lost their jobs and been cast out of society just because they are positive. All our patients have been rejected in one way or in another. They have no jobs, no shelter at all. Quite often we go and talk to their families and ask them why they have repudiated one of their members. The usual reply we receive is that the families were willing to take them back, but if their neighbours came to know that they had a HIV-positive patient in their house, not only the patient but the family would also have to move. Thus, it is not only the patient who faces rejection from the society, but the family as well.

When these patients come to us, they do not have the basic needs to live, they are mostly in a critical state of health. We offer them shelter, food and medical help. Speaking of medical help, 80% of our patients are TB-infected. We also provide systematic treatment for opportunistic infections. Last but not least, we offer counselling which is very necessary and important for the HIV/AIDS patients.

Counselling is done to face the shock that the person undergoes when he or she is first tested positive. The anger one feels. Why me ? Why did I test positive ? Why not you, or him ? The hurt that one feels because one is rejected by society and the family, because one has lost one's employment, the fear that one experiences because of multiple rejections and the fear of death are the main questions to approach. The person is terrified of dying.

Another important thing that we do for these patients is to provide companionship. One of the greatest fears that a HIV patient goes through is loneliness. A positive person is extremely lonely because he is apprehensive about sharing his status with anybody else. If I take his hand, he is frightened of rejection later. We insist on the value of friendships, and we talk about the necessity of companionship as a therapy. First of all, the HIV person is one among the twenty-five HIV people who are also positive. Being positive is a great burden on one's mind and here one is not apprehensive about sharing one's status, as all the other people around are saying “I am positive, too”. This is the bond that is built up immediately

among our patients. Another aspect of Freedom Foundation is that quite often we have self-help group meetings, like talking about each patient. Such meetings help to create emotional support for each other within the centre.

Although we started Freedom Foundation as a centre for HIV-positive patients, especially those who are rejected by their families, we did not want to take full-blown AIDS patients, but in course of months we were forced to take them as there was no place else for them to go. Hospitals would not take them, and if they do admit them, it is only for a few days : they argue they need the beds for someone else and the full-blown AIDS patients are sent out of the hospital before they have died. So, there was no place that infected people to die. Therefore, it is out of necessity that Freedom Foundation also serves as a hospice, where people who have full-blown AIDS coming from Karnataka and from other states like Goa, Maharashtra and as far away as North India, can spend their last days with dignity, compassion and love.

Freedom Foundation not only has single HIV patients, we also have whole families who are HIV-positive. We have six children who are positive. For instance, we were giving medication to a boy of one and half years, called Colomish, of whom I was very fond. I lost that little guy recently. I used to play with him. Whenever I went to the centre, he loved to hang on my shoulders, he loved to play with me and his sister Anuradha and another girl called Varsha, who are also receiving treatment at the centre. At present, we are caring for orphans of AIDS who are also positive themselves. Most of the time, their parents have died of AIDS and other relatives are not willing to take care of them.

It is worth mentioning that for the six children whom we have, we are finding it extremely difficult to find schools which are willing to take them. There were some people who asked me why I did not start a school myself for children who are HIV-positive. I agree with that, but our centre is situated outside the city of Bangalore, and we are very well-known in the surrounding area. None of the children who needed to be admitted by us were accepted by the schools.

Another problem we are facing is the shortage of funds. It costs approximately 2 500 to 3 000 rupees to look after a patient for one month. This includes food, shelter, medical help and counselling. All in all, for 25 people it costs between 60 000 and 70 000 rupees per month. It is extremely expensive. An American Jeans Company called Levi Strauss gave funds to us for the first and second years. Now we are looking out for funding for the third year. We request anybody here who has any source to get funds to help us.

Another problematic area we face is the shortage of staff. There are a lot of people in India who are not willing to work in the social work area, in the counselling field. It is not considered as a “good work”. One of other main reasons is that money-making in this field is not as good as in the commercial sector. And out of the few people willing to work in this field, only some accept to work in the field of HIV/AIDS. Again, among them, there is a very small percentage willing to work for the care of child patients. A lot of people prefer to work in education and in awareness programmes. Those who work with care are very few because it requires more involvement. In that respect, we do need a change of thinking. Care of HIV patients has to be considered as a form of prevention and this area should be looked at in that perspective. In fact, government funding organizations like UNAIDS and UNICEF have a lot of funding for education, for awareness, but very few organizations have money to give for care.

I want to touch upon a paradox : at the centre, we used to talk about the change of attitude of people. There are professionals, all working in the field of child AIDS, maybe in the area of education, maybe as concerns awareness, who come to our centre. Surprisingly, if we ask them to have a cup of tea or to have lunch with our patients they refuse, even though they know that the illness cannot be transmitted by spitting and eating from the same plate or drinking from the same glass, they will refuse indirectly and correctly. They will say “I had my lunch only at 11.30 in the morning or 12 o'clock, so I cannot have it now”. Their denigration is so transparent and disparating : AIDS ultimately challenges everybody's consciousness and conscience. We should look into ourselves first, before we ask the society to change.

Another sensitive issue regards the advertisements which appear in newspapers saying that there is cure for HIV/AIDS in Kerala. It is an interesting fact to note that nobody has brought this matter to the courts. Many of our patients who could not afford food sold everything they had and went to Kerala to have these costly *ayurvedic* medicines. Naturally, no cure occurred. Later on, they came back and were indebted. Somebody has to undertake something against these practices which have not been proved.

Freedom Foundation needs to expand. We have a 25-bed unit, but this is no longer enough. Quite often, we have to refuse clients because we are full. We need to expand. And to expand we need funds. We need to set up a separate facility, a separate hospice because patients die due to lack of facilities. Patients who are positive decline emotionally very quickly. We need to create a separate place for them to stay, because if we mingle

everybody, some are not in a position to face other patients in traumatic states. We also need to look at the care of children who are positive in a separate environment.

Discussion

Ramkumar: For HIV/AIDS patients, a centre will be enough because it can serve a larger number of persons, rather than a hospice. You say 2500 to 3000 rupees is spent for each patient : this seems rather high. If another ten patients come to you, you cannot simply refuse to take them into your institution. I would like to know more about it because the same project is planned in Pondicherry. Therefore, the organization might face similar practical and logistical problems.

Karl Sequeira : We provide residential facilities because some patients need it. Otherwise, they do not have any shelter. So either they stay in Freedom Foundation, or stay on the roadside, that is their choice. It is our duty as human beings to give them shelter, that means a place to stay at night. When it comes to the burden of a greater number of patients, I know that we have limited facilities and that we have to expand. Other facilities are being opened in Bangalore. For example, an organization in Bangalore to take care of Tamil AIDS patients. What I want to emphasize is that during all these years, nobody thought that there was a need to give care, that there was a need for facilities. When we realized this lack, we started one ourselves and hopefully there are other people who are now going to do the same, because the need is obvious.

Dr. Bobby Zachariah : You were speaking about HIV-positive patients, how they need love and care. We get all the love and affection from the family, and even when we are positive, I strongly believe that it is better we get the love and affection from our own family, rather than getting it from outside, from friends or from anybody else. It would be my request to try to re-unify the family. That is the reason why I believe that even if people are positive, they need to be re-integrated into their families. I have doubts regarding the sustainability of the approach of Freedom Foundation. When people are becoming positive and one is trying to institutionalize them as a separate group, we isolate them from the family and bring them to the institution. What happens nowadays is that people decide to be institutionalized in places like Freedom Foundation. But the number of HIV-positive people is increasing at an alarming rate. In 1992, we had two cases but now we have eight to ten cases every week. It is a question of capacity. Society cannot put all the HIV-positive persons in institutions under the pretext that they feel well inside. If you are going to start an institution in Ahmednagar, where I am working, you will have to build a place for 2 000 to 4 000 people and that place will also be full very soon. It is not a pragmatic approach to build institutions. Rather, we can try to re-integrate the people into their families. In African countries, we observe that there are only old people and grand-children. The younger generation has been wiped out and there are thousands and thousands of orphans in the community. Who is going to build the orphanages, who will give the funding? We must be with the people when they are suffering and integrate them in their families and the community. From our experience, when the community starts to taking care of these people and orphans, the mentality of the people changes. I will give you an example of one patient, called Satish, who is positive. We encouraged him and advised his family to accept him back. The family did so, but after a few days he came back saying that the whole community is throwing not only him but the entire family out because they are very frightened. We went to the owner of the family's house and to the community and explained that the disease would not be transmitted by the affected person to unaffected person through eating from the same plate and so on. Then we ate from the same plate of Satish and everybody saw this. The community started thinking and changing its mind. Later on, when an auto driver who had the disease could not work, the whole community took care of him. He died four months ago and his family members did not even have money to bury him. So the whole community came forward and buried him. It shows that nothing is impossible. Behaviour can change. If the community takes up the responsibility for the disease, then AIDS can be prevented and we would not have the question of stigma. The pertinent question is to be able to give the responsibility to the community itself. It is a difficult job, I acknowledge, but it is the only viable option left with us to cope with the problem of the epidemic.

Karl Sequeira : I agree with you. It is best to involve the community. The community must take over the situation. But we are talking about the small percentage of the community where the families are not willing to do so. That is the percentage of the abandoned patients we take care of. There will always be cases where there will be no support.

Man Respondent : Only the process may take a little long for the families and the community to accept the positive person. Here again, there is a dilemma in the terminology. For the last two days we have all been talking about HIV positive and full-blown AIDS. I do not understand that there

is any full-blown AIDS and half-blown AIDS. What is the meaning of this ? We say a person has HIV and AIDS, that is all. There are stages, I agree, but we don't say full-blown AIDS, just AIDS.

Dr Abdoul Ahmide : There is a great spectrum between HIV positive and AIDS. The person who is HIV-positive for two days may have AIDS only after eight to ten years. During these years he is harbouring HIV and he may be immune deficient. He may repeatedly suffer from infections. Regarding creating hospitals for HIV-positive persons, these persons need not be hospitalized routinely. If someone suffers from a particular infection, give him medicine. He will be cured. If he gets tuberculosis or a skin infection, give him medicine, he will be cured. But he need not be hospitalized every time, only when he is in the terminal stages. At that moment, the patient cannot eat by himself, he may have a continuous diarrhoea, he cannot be fed because he will have oral ulcers and cannot open his mouth. So he needs to be hospitalized. Routinely, the HIV patient needs no hospitalization. Unnecessarily admitting HIV-positive patients to hospitals will make them more vulnerable to the hospital acquired infections, and these acquired infections are more resistant to drugs. Afterwards, they need costlier drugs to cure the hospital acquired infections.

Man Respondent : For tuberculosis one had earlier thought about sanatorium treatment, but now it has completely changed. After the invention of the multi-therapy treatment, it is ideal for tuberculosis- infected patients to be admitted only in the terminal stages in hospital; otherwise they need not be admitted. As we know, there are going to be a lot of AIDS patients in the near future. As for the WHO theme it is not going to be “ Health for all by 2 000 ”. It is going to be “ AIDS for all by 2 000 ”. So we must be very careful. Home-care is ideal, inasmuch as not patients can be admitted to hospitals.

Usha Raghavan : This we accept. But I have a few suggestions. I know the difficulty involved with staff. We can discuss the buddy system whenever there are education and awareness programmes. Why can't we tie-up with the community who is coming forward to help the patients, then train them in the buddy system. The community can just be your friend or some of the people who are in the hospice. The buddy system can definitely work. There are three stages of training. The one who accepts the work has to be a volunteer. One can even suggest the idea as an advertisement to get people who are willing to do this, and then train those who respond. As regards the cure you have been talking about in Kerala, the doctor has been banned completely. But the fact is that he might come out with some other name. If you go to the website on the internet, you will see there are people who have started implementing care strategy, because they do not want India to follow in the footsteps of Africa.

G. Geetha : How did Pandu's family react after his death ?

Karl Sequeira : As I said, Pandu's family lives 60 kilometres from the centre. Pandu died at about 6 o'clock in the evening and a telegram was sent to his family. We wanted the cremation of Pandu to take place the next morning. The family came three days later, in spite of the telegram having reached them a few hours after his death. They said they did not have time and gave some excuses. This usually happens with our HIV patients. Not only in life are they rejected, they are also rejected in death because the family does not want to take the body. Quite often we have to do the cremation ourselves. Boys who are known to us take the body from the centre. Others do not want to touch the body for cremation. We have managed to educate the people at the crematorium, otherwise the people did not want to touch the body.

Usha Raghavan : I want to share my personal experience about a friend of mine who passed away on her birthday at 2 o'clock. We had to wait until 6 o'clock. Nobody had come to see her, even though it was just 4 kilometres from the place where her family lived.

Man Respondent : I want to reply to the question relating to the terminology of HIV positivity and AIDS which I already mentioned. I have to say that medically we know that HIV positivity and AIDS is a spectrum; it is a part of the same disease. Only for the sake of patients who become frightened as soon as they hear they are HIV-positive and panic, thinking they are going to die tomorrow, and in order to eliminate this fear, we give a separate terminology to the HIV-positive patient; we say you can still have a fruitful and good life for 5 to 10 years. When the person has repeated infections his level is AIDS, but with drugs he can still be cured of tuberculosis and he will remain HIV-positive : you have to distinguish until the moment the person is dying of AIDS. In the terminal stages he gets many opportunistic infections, he cannot feed himself, he has to be given medicines with different alliances - at that level we say he has full-blown AIDS.

F. Bourdier : Doctors may need this kind of discussion, but for the people living with HIV/AIDS, such a question is not the most important. Someone has undertaken a sociological research on AIDS care and support : he will say a few words.

G. Gopalakrishnan : I am from the Bharathiar University in Coimbatore, I am doing a PhD in the department. of sociology. My PhD topic is a social study of the awareness and spread of AIDS in Tamil Nadu. In the course of my investigations, I came across nearly 50 positive persons in Tamil Nadu. The counselling is not properly available for HIV patients. After identifying the HIV status of the persons, two married cases came to be known from me. One is from Pondicherry and the other from Chennai. Generally, people are facing isolation and discrimination. One person I met in Avinashi, near Coimbatore, did not know about his status, although his family was aware of it. The parents were, however, in a hurry to marry their son, in spite of his being positive. Sometimes there is a belief that if someone infected by the virus has a penetrative sexual relation with a virgin, he may be cured. We can see how counselling must be very important in that case. In the Namakkal area, in every village one can find at least one AIDS case. I met one case where the relatives and neighbours of that HIV person kept a distance from him. I approached them and convinced them and little by little they were ready to answer my questions. In Namakkal, I had another experience with the people of a particular house who never let me enter their door. They did not want to disclose their identity, even though I assured them anonymity and confidentiality. Once the HIV status of a person is revealed, his relatives are afraid that *they themselves* will face discrimination. This has sometimes led the HIV patient to commit suicide. There is definitely an urgent need to engage new dialogues, to speak with the families, the community and society in general.

Usha Raghavan: Talking of Namakkal I am reminded of an incident. We started the continuum of care in the area. It was a pilot project to achieve acceptance by society. One must train the community who will have to be volunteers themselves and serve the people suffering from the disease. It is based on the care book. There is no need to disclose one's HIV status to have a copy of the book. The care book is a self- guided manual to provide care at home. At the end of the book there is a directory which contains the names and addresses of the people who have been trained by the Tamil Nadu government. A list of doctors who voluntarily come to treat the AIDS patients is included at the end of the book. Earlier it was the head of department of internal medicine who trained the people, now all the 48 major taluk hospitals have a training centre for those who are willing to be trained and their addresses will be in the directory. The microbiologists and the social workers and the NGOs in that sector have the directory, and the ambulance service is also available. That is why care can be taken up in Tamil Nadu; particularly in Coimbatore, the pilot project is functioning. In that respect, Namakkal is not going to be shut down. In this village every alternate house has got HIV-positive people. Death takes place almost every other day. Namakkal is a major focus area for NGOs at present. There is one NGO working exclusively for the care aspect and there are other NGOs in this area. Similar pilot projects have been started in Madurai and Chennai. That is why, if the government starts looking at the care aspect, it would be better. Three phases are involved in the training for the buddy system and care provision. The first phase is an orientation on HIV/AIDS, the second deals with medical care, how to handle the patients when they are sick and refuse to go to the hospital, and the last phase considers how to be friendly to them. It is particularly successful in Chennai, where we have volunteers. We presently have 45 trainees who have completed the second phase of training. In the beginning we had only seven. This being a voluntary approach, and not a imposed one, it should definitely succeed.

F. Bourdier: Mr. Ramkumar, you are also working in an organization which in part deals with HIV positive people.

Ramkumar: I am counselling in Saint Joseph de Cluny's hospital. I would like to talk about counselling, rather than the care aspect. Coming back to post-counselling, many a time the HIV patients become aggressive, a lot of personality changes take place. They not only feel anger, there is also fear and depression and the feeling of guilt. Due to the anxiety of death, the suicidal tendency is highly prevalent.

Father Desmond Daniel: I work in a community-based organization called SAHAI Trust in Chennai. With regard to the care component, we have essentially two very specific roles to play. One is to provide support for the patients who are HIV-positive. Support in terms of referral services in a network with Biotic Care and the Voluntary Health Care Services (VHCS) in Adayar in southern Chennai. They are hospital-based. Second, we also have the after care where we counsel the family members and provide support to the HIV-positive patients by motivating the family and community to assume responsibilities also at personal level. We call that spiritual support. All of them have to face the reality of death, particularly those who are facing terminal illness. This is a very big challenge. Consequently, spiritual support is a very important aspect of the care component which is very much in need today. And in our learning experience, we are primarily able to touch base with a few of the NGOs working in this context. We have been networking actively among their staff and sharing our resources. Since we are community-based, we also have the support of the community by mobilizing the resources within the community to provide care with hope. Within a few months, we plan to transfer this learning experience to other community-based organizations working in the field. We also plan to organize a few training programmes in order to share our learning experience with others and to form a network with them. Those interested can contact me.

Bourdier : There is one person from Manipur who is in a position to depict a completely different situation in his state where, apparently, care is still a project.

Momoi Tonsing : Manipur has been overwhelmed by drug peddlers and most of the young people in Jangpur, from where I come, are drug addicts. In every house there is one young drug addict who is injecting drugs. I will just talk about myself a little bit. I was a drug addict for the past ten years. It was quite hard being a drug addict. The relationship between my family and myself was not very good. I was continuously taking drugs. The only place where I stopped taking drugs was in jail, and I was to jail many times. In 1990, my brother-in-law took blood from my vein for screening without any proper counselling and had it tested. In 1994, I was told that I was HIV-positive. It made me angry and I wanted to kill myself. I came to know of my positive state only when I came to stay in Sahara House in Delhi. I did not want to speak to anyone. I just isolated myself. Gradually, while in Sahara, I learnt to cope with my positive status. The sustenance I got from them, the love and care they gave me, motivated me to live a hopeful life. The people with whom I stay are very supportive. They make me feel as if I were someone special. They seem to be with me all the time. The support and confidence they have shown was the turning point of my life. I realized I had tortured myself all the time and that I should try to change myself, the way I think, the way I live, etc. I asked myself why I should not be tolerant to other people who are facing the same trauma as I do. That is why I dedicated my life to work providing care. I really want to help these people because I have started to learn to help myself. I really do not know about the situation in Manipur because most of the time during the last years I have been away from Manipur. But I have been told that the detention centre is flourishing. As I said, Manipur is the place where drugs have been used quite freely. Although the people are very concerned about it, they are not able to do much to change the situation for the drug users, as heroin is available very cheaply and freely for sale. Youngsters and even girls are taking drugs. Right now, it is very difficult to stop them from using drugs.

Bourdier : How many people are involved in Sahara as care givers ?

Momoi Tonsing : Right now we are four men and two women.

Joe Rocha : Sahara was working there but were forced to withdraw due to the political situation and the rampant insecurity.

Bourdier : Where have you been working ? When was it ?

Joe Rocha : I was there for only two months last year during December and January. But our team had gone there before me and we still intend to go back there and work as soon as things settle down a bit. In fact two of our people have already gone there to find a place for us. Since the situation there is a raging fire we want to do our best.

Bourdier : You mean there is no organization at present in Manipur which is trying to take charge of the problem of care aspects ?

Momoi Tonsing : I think there are two other centres in Manipur. There is a drug rehabilitation centre, but there is no place exclusively for looking after people infected with HIV. We did not have anything like that in Jangpur. There is one centre where our hands and legs were chained and locked. Worse than in a jail. I have been there. They also provide the persons with only one meal a day. But the guy who is running the place says it is an episode from god. He is just trying to push the water of god to us. We have a hard time swallowing such a statement. They just forced us to accept the Bible whether we wanted or not. There are some people who were chained for six to eight months. The chains were released when they were born again as a new follower of god. They forced us to pray. If we did not want to pray, we missed our meal for one day.

Bourdier : Is it a religious organization ?

Momoi Tonsing : It is a Christian organization. The owner is a man who just makes himself out to be religious. We were put there by our parents, whether we liked it or not. We were helpless. Because if we stayed outside, our parents thought that we could not stop using drugs. The centre is still there and there are still people in chains. It is in Jangpur in Manipur.

Usha Raghavan : I just want to add a few fresh facts. Three months earlier I happened to be in the same place. It has been in existence for more than twenty years. The person who is running the place is a priest and people are being chained for more than six months. I do not know how people from outside are keeping quiet, and many of them are being forced by their families to this place. When the people running the organization were

interviewed, they said that they did not want the drug addicts. It was the families who force their addicted sons on them. When asked about withdrawal symptoms in those who were chained for a long time : “ they have to come out of it on their own ” was the reply given. The third day, I was not allowed to go there as I was against them. The information I gathered from the people in the area was that people who came out of confinement at the centre take ^{he} drugs after six or eight months and again they are sent back. The people around the area discriminate against the centre, but are ready to put their children there in desperate cases because they do not know any other solutions.

Dr Subramanian : In all humility, I am prepared to withdraw my offer to Mr. Ramapandian. It is now two years since I stopped my medical practice. Even when I had the medical practice, I was a bad doctor. Where there were doctors who could say that a particular patient would die within nine hours, I could never say that. You see, if the patient was breathing, I also would think he might live for ever. That is the type of doctor that I am. If yesterday I made such an offer to Mrs Hema Devaraj, the professor at the STD department in Madurai hospital, it was out of emotion. You all might have understood that I am an emotional person regarding this and the offer I made to Mr Ramapandian, which was the same thing I told the professor at the STD department in Madurai hospital : If she would select two patients, I would try and get the drugs that offer a standstill. I did not speak up for the sake of the audience. I shall do it in my own way. Why I made this point was because I happened to know from my son that a boy of his age who was a full-blown AIDS patient in the USA was rendered HIV negative after treatment. He has put on weight so the hope that he can still live is there for others. I was just dreaming of providing life to someone, nothing else.

Part Six :

Diversities of NGOs' Experiences
and Strategies

On Destiny (*Thalai vidhi*)

S. Usha, Women AIDS Action Programme, Trichy (Tamil Nadu)

My personal story

You have certainly seen the sun which rises in the east and disappears in the west in the evening. But have you ever seen a flower which, having once lost its freshness, again blossoms and has a sweet fragrance? This you can see in the following story. But this flower, to keep its sweet fragrance, depends on you.

I was 16 years old and looked like a newly blossomed flower. At that time, Satan in the form of a lover ensnared me. I became a victim of his persuasive, honeyed words; I ran away with my lover, leaving my parents and relatives. The adage that love is blind, was again proved in my case. My lover pretended to be affectionate, but in those early days I could not recognize it as pretence, realizing it only later for what it really was.

Time passed, and I gave birth to a female child. When the child was one year, my lover went away, saying that he would come back after having seen his parents in his native place. But he did not return. For five months I waited, hoping that he would come back the next day, or the day after. Then, the house owner seriously demanded that I pay the rent for the last five months, saying that she had no hope of his return as he had in that time not even written a letter. In these circumstances, I did not know what to do. When I went to the market, the vendor of flowers, whom I knew well, consoled me. She asked, "Your husband has not yet returned?", and then said, "You are suffering now because you left your home and married the man you loved without your parents' consent. If you were under the care of your parents, you would not experience this kind of suffering. What to do? It is fate". And she suggested that I return to my parents. But I replied, "I will die rather than return home. How can I face my parents? Try to find me a petty job. With that job, I will live with my child. I made a mistake, but I do not want my child to become an orphan". The vendor of flowers promised to find me a job soon. After some days, she told me that she had found a job for me, but that the patron did not want a woman with a child. I told her, "I can work anywhere, even outside this town, if anybody accepts me with my child, as I would like to be far away from my parents and relatives". The vendor of flowers considered my proposal and replied that she would inform me within a week. One week later, she came to me and said that she could find me a job, saying that she knew someone who needed a house servant, but that they lived in Mumbai. Upon hearing this news, I was very happy that I was going to a distant place far from relatives and parents. I then sold all my household things and with that money I settled debts like rent, etc. Finally, I took all my clothes and I set off with my child to Mumbai. The vendor of flowers accompanied me. When we reached Mumbai, she called a taxi and talked to the driver in Hindi. When I asked her what had been spoken, she replied that she had asked the driver to take us to Koliwada, and had spoken with him in Hindi as he did not know Tamil. The taxi stopped in front of a house, we paid the fare and entered. A lady welcomed us. Then the flower vendor said, "You wanted a woman for house service, and I have come with her". Approaching me, the woman replied "yes, yes" and asked me, "Will you do the housework well? You are just like my daughter. You can behave here just like at your own house. I will fulfil all of your needs. Now go and take a bath and eat. We shall talk later about the other things". At about four in the afternoon, the vendor of flowers approached and said, "I leave Mumbai today. You behave well with the owner". She then left.

At about six that evening, the house owner gave me a new dress and asked me to put it on. Although I informed her that I already had some good dresses, she insisted that I take her dress. The conversation turned into an argument. Only then did I realize my true position. Finally she told me angrily, "You are not here to do housework; you are here to satisfy my male customers. I bought you from your friend for 10 000 rupees". I was shocked at these words. For the second time, my life had turned to the worst. I implored the lady, "Please, I will do all the housework". I pleaded with her, I begged and wept. But it was no use. I was cursed and also beaten.

Other young women of 17, 18, 19 years were also staying in the same house. They consoled me. "Your case is so much better than ours. You have come here as a woman after marriage; we have been here since we were very young girls. We were kidnapped and sold here for money. We also cried and wept; we were beaten with heated sticks." They showed me the injuries made by her because of their disobedience. I was further shocked at hearing this news. Then they advised me. "We can never escape from her. If you obey her will and orders, she will take care of you in a better manner; otherwise she will mistreat you. You have a child. The woman who came with you in the morning sold you to her for 10 000 rupees. To leave this place, you have to reimburse that amount. There is no alternative. Obey her. It is your fate."

From that day onwards, I lived in hell. I passed two years in that hell. I was used for the sexual pleasure of forty to fifty men every day. I could not give mother-milk to my child. The customers or the house owner had left me no chance even to see the child. It was very horrible for me. I wept from the bottom of my heart. I detested myself and asked why I lived. Even after midnight, I was compelled to give sexual pleasure to customers. It happened like that every day.

Eight months passed. One day I came to know that I had become pregnant. The patron insisted that I destroy the child. I begged her not to force me to do so. Finally she accepted, on the condition that I would not stay in the house after the delivery of the child. I accepted this proposal. Then, the female child was born.

I became the mother of my child by an unknown father. Three months after the birth of my child, the patron gave me some money along with some jewels and sent me off to Madras. When I arrived at the station in Madras along with my two children, an RPF (Railway Police Force) approached me and asked, "Nobody has come with you?". I just replied by nodding my head. Then he asked me where I wanted to go. After a slight hesitation, I replied that I did not know where to go. He then asked, "Did you leave home due to a dispute with your husband". I said to him, "Please do not ask me questions. I feel much disappointed in life. If you want to help me, then tell me; otherwise please do not give me any trouble by asking many questions". To which he replied, "If I can, I will help you; but tell me what kind of help you expect from me". I said to him that "first, I urgently need to rent a house to stay with my two children". He said, "Okay. Wait in the ladies waiting room of the station. I finish my duty at one p.m.; then I will come". He brought me a coffee and left me in the rest room. He came back at one p.m. and provided us with lunch. Then he took us to his house. There he told me, "The grocery shop and the market are very near. For the time being, you stay here till I find you a house for rent; then you can leave. I will stay in my office." Then he called the house owner and introduced me to her. He informed her, "This lady, whom I know, will stay here until I find a house for her to rent. Her husband has gone to a distant place because of his job. He will come back soon." One month passed. He found a house and had me settle there. He helped with what I needed.

Then I came to a conclusion. I told the house owner that my husband was already dead and I would not return to my parents because I had married the man that I loved against their will. The railway police guard visited me frequently at my house. My children also felt affection for him. One year passed. During this time, we fell in love. Then we found another house and settled as a

family, husband, wife and children. We lived together happily. He also behaved affectionately with me and my children. After six months, I became pregnant for the third time. One day, when the child was six months old, he told me that he was going to see his mother and that he would come back within a short period. Days passed and became weeks and months. A year passed and he did not return. But the house owner did not ask me to vacate the house. She had pity on me and said, "The way he left you! He never disputed with you and he also had affection for the children. What happened to him?" She was worried about my situation, but never thought to turn me out.

When I thought about my fate, I smiled in my heart. I thought that all were good; everyone came forward to help me, but fate never let anyone stay with me more than two years. That's all. What to do? Everything depended on fate.

Then I found a job. When I went to work, I left my children in the care of the house owner. My salary was only 150 rupees, but I paid 120 for rent. I did not know how to manage with the remaining sum of 30 rupees. I began to work overtime, but only for 100 rupees more. It was not sufficient. I began to think about my situation and came to a decision. I had to earn more money. I had to buy some jewels and other things; I had to arrange for the studies of my children. To settle these problems, I entered willingly into prostitution. To protect myself from society, I let everybody think that I was working hard to support my children. I earned more money, and sent my children to school. I fulfilled their needs. I saved money in the bank. I also did a little business and increased my savings. With that I bought a piece of land and built a house. The visits of my relatives also increased with the increase of money. They did not think about how I earned so much money. They came to me as I became rich. Nevertheless, I was very fearful that my children would one day come to know about my activities. If so, would they reject me? With these worries, I spent many sleepless nights. I was then 30 years old. I slept well until I was 16. After a long interval, at the age of 33, I began to again sleep. I did not sleep calmly for 16 years.

The 15th of February 1992 is an unforgettable day, a golden day for me. I am very grateful to my close friend who is responsible for that day. She informed me that she had learned about an organization which was working with the aim of preventing the spread of AIDS among prostitutes. Former prostitutes were recruited to work with them. So she gave me the address to find work there. The next day I went to that organization, namely the South Indian AIDS Action Programme (SIAAP). At that time some ten people were working there. I joined that group; my friend and I were the only former prostitutes. The salary was 150 rupees. But without receiving any salary, I worked voluntarily. When I initially joined the organization, I worked as a peer. Then I became a chief of the peers. I subsequently did fieldwork. Then I became a member of the office staff and a member of the organization. In the course of time, my salary gradually increased from 150 rupees to 6 000. We worked well and distributed 120 000 condoms per month among 8 000 prostitutes through peers (200) all over Tamil Nadu, Karnataka, Andhra Pradesh and Kerala. We attained a record in distribution, 15 million in one year. We, the prostitutes and peers, have achieved the aim better than both government and non-governmental organizations. Even today, we hope to achieve more than this.

Nobody has given us any training to do this work. It was done through personnel experiences and innovations. They gave me the addresses of four or five voluntary organizations and told me to organize them to work in this field. Though it was in an unknown place where different languages were spoken, I selected the best voluntary organizations and made enquiries among scooter and *rickshaw* drivers to find out the areas of prostitution. I went to these areas and talked about and explained STDs, the spread of AIDS and the use of condoms. I found some talented and freely talking women and gave them training.

One may ask, how I could work well in a place where the people are speaking different languages. Wherever I go, I meet only my society. The women who speak different languages practise the same profession. Everywhere we can find women coming from different parts of the country, so that in all states, I will meet women prostitutes speaking Tamil. First, I speak about and explain my job. Then I have the women to speak to others. Someone translates the reply into Tamil. Furthermore, I am also able to understand their explanations from their expressions and gestures. I have improved this skill day-by-day. I have also worked as a counsellor in the department of STD, HIV/AIDS in government hospitals. I have gone to prisons and educated the women prostitutes there. I have received no training for this. All the posts I have held were obtained through my talents. I have good relationships with both government and non-governmental organizations, police and politicians. The prostitutes in Tamil Nadu elected me as their president. I subsequently formed an association for women prostitutes with the collaboration of all prostitutes. Now I am the president of this association. The National Women's Organization gave me some importance and selected me for the project of prevention of child prostitution. I completed this project and presented my observations in the form of a book at a conference held at Goa. I thank the National Women's Organization, Delhi, and the Director of the Tamil Nadu AIDS Control Society and its other staff members. I also thank the organizers of the seminar held in Pondicherry on 7, 8 and 9 November 1997 for allowing me to present my ideas in the form of a seminar paper.

When I do this kind of work, I remember one or two songs.

The first is as follows:

When you are present among the great people,
you should be honoured;
As you are perfect
Every one should praise you.

The second song is as follows:

What has the nation done for you?
Why do you ask this question?
It would be better to ask yourself
What have you done for it?

I hear always as an echo these kinds of songs. I have today worked up to this level because I have experienced a lot suffering. That is the reason for my growth. Nobody has given me any training to do this kind of work. I think always about my sufferings. I work voluntarily for my society, also so that children do not have to experience what I have. I pray to God to give me a long life to serve my society. I am very happy to do this work. Furthermore, I am proud of saying that I am a former prostitute. If I were an ordinary woman of this society, could I do this work? It is doubtful. I am ready to dedicate my soul until death to work in this field with the collaboration of non-governmental organizations. Hereafter, this flower will blossom as a newly fragrant fresh flower. I offer this flower at your feet.

In the past four years, several actions have been initiated to face the problems of AIDS at national and international levels. Many organizations have been created to this purpose.

In Tamil Nadu, some 2 000 voluntary organizations are active in the prevention of AIDS, because the World Bank came forward with « 100 million dollars » to help. The Ministry of Health has also formed an organization, the motive of which is to receive funds from the UNO. This work was first begun only after a grant of 10 crores of dollars.

A WHO Consultant provided an opportunity to do research on women engaged in prostitution. But what happened? An organization was formed in Chennai using students. Immediately the Tamil Nadu government and WHO granted funds to this organization. I will give later the details and the results. The developed countries have for the past 30 or 40 years influenced the underdeveloped countries.

Thirty years ago, according to suggestions of the developed countries, the revenue programmes were started among poor women in villages, after which the savings and interest programmes were proposed. Then they announced that it was to empower all women. Following this, they started the programme for environmental protection. For the past five years, NGOs have been working under the pretext of networking.

Recently, there was news that 400 women, including children, were arrested in Bombay. I have requested all NGOs not to present this fact as one would present a fashion parade. I am afraid that if the programme of the prevention of child prostitution is given to NGOs it will not have sufficient participation support. I humbly request that not only proposals beautifully written in English should be taken into consideration, but also those written in Tamil, and that the voices of the poor and affected women be heard.

A bitter experience

For the past six years, I have been working amidst and in contact with many NGOs. I have worked in collaboration with fifty NGOs in Tamil Nadu, twenty-five in Andhra Pradesh, five in Karnataka, twenty-five in Kerala, and three NGOs in Maharashtra. I have also worked with 2 000 sisters, including children, engaged in prostitution. My motive is that STD/HIV should not afflict women.

Mahatma Gandhi started the trusteeship with a good motive, but today it has become an organization working with a profit motive. Social welfare, sacrifice, and thinking and action for the lower classes have disappeared. The motives are to develop the organizations and to earn more money. They cause NGOs to suffer, along with the women working with them.

For instance, there is an NGO in one of the biggest cities in Tamil Nadu which is involved in the business of prostitution in its office, to which government officers and customers are invited. The Tamil Nadu AIDS Control Society still grants funds to that organization. Not only this, some NGOs direct that prostitutes have sex with them. If the women do not consent to their wishes, they threaten to terminate their jobs.

Another organization in Tamil Nadu invited prostitutes and provided them good food and fifty rupees each; their photographs were taken and appeared in the newspapers. One woman, who was identified by her neighbours from the photograph which appeared, committed suicide. Another small organization in Chennai brought male children to its office, provided them with alcohol and then forced them to have homosexual sex. Some who knew of this matter informed the NACO. They were warned that their grant would be cancelled. A half million dollars have

been distributed to NGOs during the past six years and they have begun to work for the prevention of AIDS.

What expectations can one have of NGOs based on the examples given above? There are so many NGOs working for the prevention of AIDS, but based on my personal observations, they spend only 25 per cent of the grant as salary to the working women, and take 75 per cent for personal expenses, while the government provides all other necessary things like condoms, medicines, injections, etc. Apart from small and punctual donations, NGOs hardly spend anything for the ladies in prostitution. Initially, the NGOs did not have cars or their own houses; after having received grants, they suddenly have cars, bungalows, beautiful dogs and plants to decorate their houses. We should not accuse all NGOs, some are working well and I have had the opportunity to meet them. However, some organizations do not want the development of work for prostitutes or former prostitutes, but want them to remain prostitutes or be servants in life. With jealousy, they insult us: "I am a fair lady and have an MA or other degrees. I have a car, a bungalow and a good name in society, but what you have got? You are a prostitute; the police will arrest you and file a case against you, but they do not touch us. Think of how you were yesterday and how you are today! You can continue in this job if you obey me. Do what I say, otherwise go and start work with an NGO, but I won't help you. Even if you should do that, the AIDS society will ask us to recommend you for the granting of funds. At that time, you can do nothing". In such circumstances, we do not know what to do. It is for you to advise us, taking decisions is in your hands.

The director of an organization says that she is fair, that she has a car, a bungalow and a good name in society. But to do this work one should have tolerance, boldness and experience. Then one can do this work well at the level of villages, towns, states and the nation. Even internationally, one can work among the people to prevent AIDS.

What is beauty ? I saw the beauty of Mother Teresa. Although she was born and grew up somewhere else, she served and sacrificed herself to Indian society. She became known throughout the world but continued to serve until the end of her life. That is beauty. Sarojini Naidu is another example of beauty. She took care of sick persons and treated them with a lamp in her hand during the night. For that reason, she was referred to as the lady with a lamp. Here also is beauty.

Recommendations

We, prostitutes and former prostitutes, work for the prevention of AIDS on the state level. Hence, we need help directly on the national level. It is recommended that:

- funding should be granted to an organization when 75 per cent of the workers are comprised of women prostitutes ;
- before granting funds to any organization, it should be inspected or observed;
- a lesson should be taught by punishing NGOs when bad behaviour is evidenced;
- a chance should be given to women workers to explain their grievances and their needs;
- when government organizations / NGOs grant or distribute funds, 25 per cent importance should be given to the NGOs and 75 per cent to CBOs;
- when a proposal / project is received, it should be considered whether the persons are well-known in society and experienced in this field, and not whether the persons have cars, bungalows,

degrees like an MA, beauty, personnel influence, or whether the proposals are written only in English.

NGOs and CBOs

Four questions are raised : 1) What is the purpose of a CBO? 2) Why are CBOs necessary? 3) Which objectives are strengthened by CBOs? and 4) How do CBOs strengthen their objectives?

The work will become effective when the person is experienced and well-known in the society where the work is to be done. This is an observed fact from my own experience. The person who is integrated in a society is well acquainted with all matters of that society. CBOs will assume all responsibilities for that society, if they are started independently. Otherwise, they become dependent on others. Once they have got started, many leaders will emerge from the public. Because CBOs are not consulted by outsiders regarding the problems and needs of society, many good programmes and suggestions come to nought (this matter should be examined).

What is sugar? Sugar means sweet. We say that something is sweet only after having consumed it. Likewise, the problems of society are known to those persons integrated in that society. NGOs and government organizations administer everything today, yet they have still achieved nothing because they must first thoroughly understand the society in question. Talent is also needed for this work. The first important step is that responsibility should be handed over to the CBOs which are familiar with the needs of the society. In that way we can save time, money and hard work.

Some NGOs receive grants based on CBOs, which never derive any benefit from the grant. If grants were given directly to CBOs, women in that society would perhaps benefit. It is usually middle-class people, educated and speaking English, who belong to the NGOs. If anyone from a CBO speaks English, those from NGOs try to stop their development, and thus the former have become fearful of the NGOs. They are asked questions. NGOs work on the basis of funding and give importance to it. But CBOs are not in that situation and will work as best they can for their society even without money. Government organizations have no fixed ideas in their plans and they change their programmes in favour of NGOs. But CBOs with fixed ideas have greater chances to work effectively, because they must account to society if any shortcomings occur. But NGOs need not reply to anybody; still today we are afraid to question them. And, when we do, they reply that they need not account to anybody and ask us who we are to question them.

In effect, when CBOs work with NGOs, they fear the latter, who are to be respected. If CBOs work independently, their society will benefit. There are more chances to work effectively according to their needs. The NGOs do not let the CBOs do their work and give false information regarding the society.

One NGO, for example, has been working for seven years. During this period, it might have accomplished many useful things and women's society might have been able to develop itself. But they have done nothing. Today, they say they are not able to nominate anyone, not even for consultation regarding HIV/AIDS. Once, they asked a social worker, holder of a masters degree, to work in the government hospital for three years. You can understand the facts from this. NGOs do not consider us and are always mentioning the fact that we cannot read or write and that we are stupid. It is true that we cannot read or write, but it is laughable to hear that we are stupid. This

organization might well have taught these women to read and write during the last seven years, but it did not do so because it does not contemplate the development of women's society. But it makes appearances of considering them. It says that we should ourselves start an association/organization to develop ourselves without the help of others. When we, the prostitutes, do organize ourselves to start an association, it is suggested that we postpone this activity for six months. In the same way, they have stopped our attempts to start the association several times. But we have awakened now. We have now started an association for prostitutes and have already begun our work. Now we educate our women in our office. To do this, we negotiate with the Collector of our town. We try to get ration cards, free land, etc. Then, we arrange for the education of our children and a hostel for them. We also work for the prevention of child prostitution. These are facts. We have done it; CBOs have achieved what the NGOs could not achieve. We assert that we are the only persons who can achieve these objectives.

Strengthening CBOs

If someone from this society would come forward and act, it would set an example. For this, I am the example. The question raised in this society is, why do we not do the same as is done by the NGOs, as they are like us.

The corruption will be less because they (the CBOs) will raise questions. If we do this work, the chances are greater that their needs will be understood.

Society will question with boldness, making use of its rights, like a mother who provides milk to her child when it feels hungry. They will ask us with authority and affectionately, "Don't you know what problems we face from day to day? Why have you not yet done these things? If you are not able to do it, let us to do it. Why do you do all the work? Give us some work to do".

A daughter disputes with her mother affectionately. What do NGOs know about our society's problems? The people will think, "How can we question them? There's no use asking". If there is a society, there is a history behind it. Those who belong to that society can understand that history. So only CBOs can understand and can accomplish the work. NGOs cannot have the capacity to understand. Only the person belonging to a society will work hard for it. But the NGOs are not the same. They are outsiders; there are no relations.

Even if the mother beats or tortures her own child, she is always its mother. Even if after the death of the mother, the step-mother takes care of the child affectionately, she will not become equal to its true mother. Similarly, this is the difference between CBOs and NGOs.

Discussion

Dr. P.K. Das : We perceive a lot of emotion in your voice. We may understand your bitter experience, but why so much suspicion of voluntary organizations ? Don't you go too far ?

S. Usha : For the last six years I have been working in this field. I started my work with the South India Aids Action Programme. Now I have my own organization which is based in Trichy, working among women in prostitution. My main concentration is on studies of HIV awareness, condom distribution and taking the women who have been in prostitution for STD treatment and counselling. Apart from that, I am concerned with their basic needs like education for their children and land and getting them ration cards. Furthermore, concentration is on the prevention of child prostitution. In my six years of experience, I find there is a difference between non-governmental organizations and community-based organizations. Of course, one should not blame systematically voluntary organizations: some NGOs are doing good work. I am just sharing a personal experience. Why is there a need for community-based organizations (CBOs) ? What are the ways to strengthen them? Why do we have to work on them? Community-based organizations are started by the people in the community. Other people cannot understand the community. Until and unless the CBO is involved, there cannot be a precedence. Outsiders will never understand many of the difficulties of the community. As I explained in my presentation, you know that sugar is sweet only when you taste it. In the same way, only the community-based people can understand the community from inside. The only thing is that they have to be encouraged to take up CBOs.

P.K. Santosh : But can't NGOs and CBOs work in synergy?

S. Usha : Both non-governmental and governmental organizations are contributing to changes, but I do not think they will achieve it, because they have not understood the community. At the same time, to understand the community they need some skill. If they ask the community-based people to do the basic work, it is successful because the latter understand their community. This way one can save time, work and money. Nowadays some of the NGOs claim that they are working among the community-based people. From this perspective, they get a lot funds which do not reach the community itself. If the same funds were given to the CBOs, it would certainly reach the community, particularly in the case of women in prostitution. Moreover, most of the NGOs speak English and this creates fear in the community. When the CBO people want to speak out, they are put down by the English speaking NGOs. Such a linguistic gap creates fear. The community people get alienated from the inability to express what they feel in a proper language. Language is a power. The community is put away from the NGO. In return, they are not able to question the NGOs; whereas if it were a CBO, nobody would be scared of the people involved in the work. They could question their fellows freely. On the other side, the NGOs will work when there is a lot of money available, but CBOs will work voluntarily because they are sincerely concerned about the welfare of the community. They work even without money. NGOs speak for a single programme and, depending on the need of the community, they change the programme. That is not the case with the CBOs which belong to the community and work exclusively for the development of the community at large, as they are answerable to the community.

David Thiagarajan : On certain points I follow you, but are you sharing only your personal experience or commenting about the CBOs and NGOs in general? You are not always clear about this.

S. Usha : It is my experience as well as the experience of others. If the CBO does not function properly, it will lose its name in the community and it will assume the responsibility. This is not

the case of the NGO. The prestige of a NGO does not depend on its popularity among the population. I have seen many times that whenever the project does not work, they tend to blame the community. For example, one of the NGOs located in Chennai has been working for seven years with women in prostitution, but they have not yet achieved anything much. Whereas a community-based organization could have done a lot of work within that time and would have wasted less money. The women would have also come forward and sought assistance without any hesitation. Now that NGOs has taken up counselling and talk about STDs, HIV and AIDS, they say that the CBOs are not capable of doing the counselling because they are not professional. But we had done counselling for STDs, HIV and AIDS- infected people in one of the government hospitals continuously for three years. Then, we were thrown out and, instead of us, persons who had been granted a diploma in social work were appointed for counselling under the pretext that only well-trained persons can do the work well. We receive so many insults : they blame us for not having courage, they look at us with disdain as we are supposed to be illiterate, unorganized and unreliable. This is not true. We might not be literate : that does not mean we do not have the courage to represent ourselves and the heart to help others. The NGO I was talking about, which has wasted seven years of *blah-blah*, could have educated the women and inculcated courage in them, but they have done nothing. They want to keep the power for themselves. The NGOs do not concentrate on the community, but pretend that they are concentrating on the community and uplifting it. Whenever we wanted to start a *sangam* (association) and approached them for any help, they would say that it was not necessary and can be done later on. In this way, many periods of six months have passed, but they have never united us. On the contrary, they tried to divide us. Now we have woken up and brought the women in prostitution together to formed a *sangam* and started our own empowerment. The matter was taken up with the district collector⁷ and we started providing education to the women in prostitution, helping them to get ration cards and a decent place to live. We also take care of the education of the children of these women and consequently we prevent child prostitution, too. All that could not be done by the NGO has been achieved by our CBO. Apart from this, we also help in obtaining the release of women who have been arrested under the Immoral Traffic Act as soon as we get the news. We help them to go to the judiciary if they have been forced to take an HIV test, and to get bail if they have been arrested under a non-bailable charge. There are a lot of things that can strengthen the CBOs. I am an example myself : in my community, the women seeing me want to ameliorate their condition.

John Dalton : I think the NGOs are quite dedicated to their duties. One cannot say the CBOs are always better. My understanding is that NGOs and CBOs are entirely different. The objectives of the NGOs are to identify, to prepare, to programme and to implement in collaboration with the local community, to train them and gradually withdraw. There is no conflict involved here. There is no motherly or step-motherly treatment involved here.

Dr. P.K. Das : If the community-based organizations had been doing so well, then India would have been a different place. NGOs are not completely foolproof. They also have their flaws. At the same time, each organization has its own advantages and disadvantages. I also work with a CBO, but no one goes to the CBO for assistance. One cannot conclude that CBOs are the only remedy. One cannot say only this person should do that and that person can do this. We are all partners. There are certain roles for the government, certain roles for the community and certain roles for the NGOs. Therefore, instead of pointing at each other's flaws, we should come together and all three organizations should work in synergy. Each organization looks at the problem from its own perspective, so all of us have something to give to the others. As for the second issue about the Immoral Traffic Act, your objections are good. Even I, as a director of a national agency, fight with the police establishment. Until you bring the legislators to make a legislative change that no woman can be booked alone under the Immoral Traffic Act, but only along with the client, the act will be discriminative. Punishment cannot be given only to the women, but must be given to the client also. If you can do this you solve a part of the problem. But how many police stations will you have to go to ? You cannot prevent this till there is some legislative change. This is the role of the government and NGOs, to act as a lobby for a change in the law.

⁷ The highest administrator at the district level.

G. Geetha : Mrs Usha is presenting a complaint against the NGOs. We are prepared to listen and, as suggested by Dr. Das, why arrest only the two parties ? The procurer should also be brought to book. This is something that cannot be done overnight. The procurer makes more money out of the sex trade than either the man or the woman. So our legislation should change to this effect.

John Dalton : Thank you Mrs Usha for those stinging blows to the NGOs. A very courageous presentation. You say the truth, we cannot deny it. NGOs do waste a lot of money. I am an outsider, working in Andipatti near Madurai. Here, there is no CBO, there is no women's organization. We are trying to form a CBO in the area, but it has been very difficult. I believe in CBOs too. But it is taking so long for an NGO to try and form a CBO.

S. Usha : I will go further. The women involved in prostitution face a lot of difficulties. They are not given medicine. They have to walk a long distance to go to the hospital. At the same time, the NGOs live in luxury : they travel in cars, have bungalows and colour TVs. They take photographs of women involved in the sex trade and publish them in the newspaper. Not only does this spoil the business of the women, but it also leads to a lot of social trouble. NGOs, instead of doing anything good, create havoc in the community. But one has to differentiate between the NGOs who are doing a good job and those - albeit the majority - who are not doing anything positive. Because of the NGOs who mess up the one's that are doing a good job, the public is losing faith. There should be a board of control among NGOs. Two days back, we were speaking about NGOs and networking. It could be a relevant point to use the network information system as a way to prevent the bogus ones from acting indiscriminately. Then, nobody will be blamed for lethargy and money swindling. You also speak about counselling. The counsellors employed by the NGOs ask indiscreet questions such as how many clients they attend in a day, how much money they make and on so forth. Is this counselling or moralizing ? The women object to answering such questions. It is none of their business to know all these details. Sometimes, the counselling process is reduced to mere advice like : " Be a good woman and stop your ugly activity ". Hence, the women are against the counsellors.

Experience and drawbacks on intervention with sex workers in Madurai.

David Thiagarajan, Image, Madurai (Tamil Nadu)

I am the Secretary of the Institute for Mass Awareness, Guidance and Education (Image). We started the organization in the year 1991. Previously, in 1975-77, when I was a student doing post-graduate work at the Madurai Kamaraj University, I started with some friends a home for girls who had left their families because of dowry problems, social conflicts, separation, incompatibility with relatives. The name of the house was Arulagam. At that time, I was president of my college and I received some funds from abroad and started to ameliorate the Arulagam, which initially housed from 25 to 60 girls. Now it is situated in Pasumalai, near Madurai, and the home is run very nicely. Nobody stays there for a long period; women stay between six months and one year.

After completing my post-graduate work, I started as a full-time social worker and worked for the following 15 years in different organizations. As soon as we started Image in 1991, it had good chances. We began with awareness work in villages around Madurai. We started the Image *Sangam-s* in ten villages close to the city. With the help of a group of dedicated advocates, we conducted free legal-aid camps. We were getting a little assistance from Literacy India Trust. Consequently, we opened and managed non-formal education centres in the ten villages. At the same time, we were given the opportunity by another Chennai group to attend an AIDS seminar conducted in Madurai. I actively attended that conference, where I had the opportunity to interact with many people. They gave me a chance to conduct a random survey in Madurai city over a period of six months. With the help of two brokers, one male and one female, we did the random survey of the prostitution pattern in Madurai city. Such a baseline could be done because we had good connections. The purpose was to identify the geographical and social distribution of the various type of prostitution and to answer some basic questions, such as : How much do the girls earn? How do they spend their money? To which extent are they exploited? Later, we started a free STD clinic. It was the first free STD clinic in Madurai City. Ten to fifteen girls regularly came to the clinic for treatment.

Prostitution in the city

I will briefly discuss the nature of prostitution in Madurai. The people involved in the sex circuits use jargon like *maadu* (cow), *taxi*, *item*, *ticket*, *jadi* to refer to the girls. Some professions have their own vocabulary, for example the auto-rickshaw drivers, the petty traders, etc. Broadly speaking, in Madurai city the sex circuit is composed of eight to nine different types.

The street worker type

The street workers operate at the bus-stand, in the market areas, on the streets, from nine in the morning until they go home at five or six in the evening. During this time, they will meet a minimum 20 to 25 clients. They take their clients to the nearby lodges; the clients have to pay them directly. Every client pays the rent and subsequently the lodge owners earn a lot of money. The time limit allotted in the lodge will be a maximum of five minutes. Sometimes they choose a one-hour contract, if the client is ready to pay the price. Normally after five minutes, the lodge manager knocks at the door and requests both client and sex worker to get out. Sometimes, when the woman comes out she finds her next client waiting for her at the door of the room. Due to the time limit, condom use is neglected. The lady will also think that if the man wears a condom, he will take more time to ejaculate.

The highway sex worker type.

They are just a few, about 25 to 30, in comparison with some other places in Tamil Nadu. They work in very difficult and hygienic material conditions. There is no place to wash, no place to change. These ladies go neither to a lodge nor work on contract basis. They will attend sometimes three clients at the same time. If we except the roadside, one of their main pick up points is the movie theatre. They will go to the first show with the client and after the show they will go back to the highway. There are four highways near Madurai. On each of them, there are only a limited number of sex workers. At present, Image has no contact with those particular sex worker;

The brothel sex worker type

There are many brothels in Madurai. Madurai is a small town with more and more extension areas. In every brothel, there will be three to six sex workers. There are two kinds of brothels :

1) The broker type. The brokers bring the girls from another city or from another brothel house on contract basis. The woman will have to stay there during the day and return home in the evening. Some stay there the night, but rarely. They are in the sex business without the knowledge of their husbands or parents. Such a type of brothel is different : to satisfy the clients' taste, a broker will be in touch with two or three houses. One of my very close friends is a broker and he covers from ten to fifteen houses at a time. He changes the sex worker on a rotation basis and keeps them in one place for 15 days. The clients can change girls or visit the same one.

2) The contract type. Another kind is in the lodges where the girls are brought on a contract basis for fifteen days or for a month. The girls are not allowed to go out of the lodge before the contract is over. If something goes wrong, they lose all the money they would have got at the end of the month.

The housewife sex worker type

Sometimes slum girls and women come to the lodge or brothel and go back in the evening to their homes. In that case, they are free to come and go whenever they want. Most of time the housewives are occasional sex workers. They may have another work, either irregular or that does not provide them sufficient with money to face the family's difficulties.

The family girl type

For example, an unmarried college student in her twenties. She is living in her parents' home and is occasionally involved in high-class prostitution. Such girls belong to the lower-middle class and the middle class. They are called " Kinetic Honda " girls in Chennai because poverty is not the reason for their involvement. They are attracted by the new commodities society proposes, but are unable to obtain them through the family circuit. The girls charge a lot, are very discreet, have their own network and are quite impossible to be in touch with unless one is a client.

The bonded sex worker type

Wife or daughters from middle class families who are forced to prostitute themselves to reimburse the debts and loans of the family. They are forced to have sex free of charge as the relatives are not in a position to pay back the money. Sex with the girls is considered to reimburse only the interest.

Other types

The call girl type : This category corresponds to the high-class prostitution. It includes both married and unmarried women.

Men prostitutes (with men or with women). Social networks are well-organized.

Ali (transsexual) prostitution : A common feature in certain areas of Madurai.

Small world

Another particular custom practised in Madurai is the initiation into sex of a girl whose sister is already in the prostitution. It is the occasion of a special ceremony performed with various rituals that Mrs Jaya Karuppaye will explain to you in detail later. There are many rich fellows who are ready to pay 15 000 to 20 000 rupees for a night with a virgin. I was recently introduced to a virgin girl whose sister was searching for her a client. With the money, the family will buy some jewellery (dowry) and marry off the girl. Even though we gave counselling to the girls and their families, we were absolutely unable to stop this practice. In fact, such a sudden amount of money changes the whole life of the girl and of her family. The marriage problem is solved, the family need not borrow money from outside and, furthermore, it is not considered as an act of prostitution (being unique).

The children of sex workers are facing tremendous problems. It is not rare that children of four/five years or older remain present in the same room when the mother has sex with her client. She has no place else to keep them. One can imagine how dangerous it is for the children and to which extent they will be psychologically affected. Sex workers sometimes ask other sex workers, brokers or old women, to take care of their children. These people have to be paid about 20 to 30 rupees for their services per day. The worst for the children is that they have no chance of getting educated because sex workers usually do not stay in the same place for a long time. They are frequently employed on a contract basis and change places. Ninety per cent of the children of sex workers have poor chances of getting a proper and regular education.

Recently, I appointed a female post-graduate student as my assistant. I took her to the field and introduced her to a few brokers in Madurai. Within three days, the news of her beauty was known and some brokers were already trying to enrol her into prostitution. Some of them thought that she was a new girl in the profession and asked her to have sex. The girl immediately resigned from her job. That is why we usually select a few educated and bold women who are (or have been) in the profession. We train them in the AIDS awareness programme and explain to them how to distribute condoms.

We are facing a multitude of problems in our organization. It is a known fact that we are running a free STD clinic, and when any girl comes to our office, the brokers at once start to get her and fix up clients near our office. It creates a climate in which the neighbours and the women get suspicious. We are not only involved in AIDS field, but also in awareness programmes. Thus, when girls come to our office for either purpose, there might be brokers who talk with them in the office and take them to the bus stand for work, as a consequence of which, the police suspect our work.

We also have problems with the local rowdies (youngsters either employed or not by the local Mafia). Whenever we organize awareness programmes, we have to inform 250 to 300 sex workers : only then we can get about fifty to sixty sex workers to turn up for the camp. Sometimes, when they are coming for the meetings, the clients pick them up at the bus stand and take them away. Even among the fellows who visit Image office, a few will take the girls from there without our knowledge.

Being known in the field of prostitution, it has been very difficult to rent a house for the office, the STD clinic and a place to conduct awareness programmes. If ever we do get a house, the owners will make us vacate it as soon as they are aware of our activities, due to the above problems. Consequently, we cannot get a permanent rented house for running the STD clinic or awareness programme because the owners will immediately ask us to leave when they see so many girls coming to our office.

Some NGOs want to challenge us because they would like to undertake the same work as we are doing. It has been very difficult to control our own place : there are some people visiting our office deliberately to cause problems.

Personal involvement implies familial concession. I have two children and when I would go out with my wife, people mistook her for a sex worker. Since then, she never comes out with me. My wife asks me not to involve myself in NGO activism because when I meet a girl or a sex worker on the road whom I know through my profession, she might ask me to get her a cup of coffee, or lunch, and another might ask for alcohol. I have to oblige them in order to remain in contact and be a respected person in my social work. It seems ridiculous, but such things are common. Most of the time, my wife and I never go anywhere together and I try to avoid travelling by bus with my family. These are other problems faced by and my staff and myself as a result of being involved in the field of AIDS.

Discussion

G. Gunavathy : How about the women infected by the virus? Are you in touch with them? And what is the present situation regarding blood bank regulations and control of blood?

David Thiagarajan : For positive persons, there are other organizations working in the area care and support in the city. So far, we are not involved in such activities but it is one of our future projects. But we know some women in prostitution who are infected by the virus. In that respect, we provide them advice in terms of sexual behaviour, but for counselling we refer them to government doctors who are skilled in doing this. Now, coming to the risk of contamination through blood and plasma, the present situation in Madurai city is that there are nearly 125 private blood banks. I came to know that the government is taking and testing blood every month and getting the current information. In all the blood banks, ten to fifteen new cases are coming monthly. Most of these infected persons belong to the low-middle class. They form another high-risk group. They cannot pay 225 rupees for the Elisa Test or

1 200 rupees for the Western Blot. So, the middle class people are testing their blood at private blood banks. In Madurai Rajaji Hospital, if anyone wants his blood screened voluntarily, he will be first given counselling, and then his blood will be screened. Generally, the poorest people go there. But one cannot say that the concept of voluntary testing is known to the general population. Most of the persons are not aware of their rights.

Alice Pushparaj, Navajeevan Asha Project, Vellore (Tamil Nadu)

Navjeevan Seva Mandal is a registered voluntary social service organization, established in 1984, which works for the relief and welfare of the poorest and most backward people of the Indian communities. The prominent projects are children's homes, community development, medical and health care vocational training, animal husbandry, specific disease control and rescue and social rehabilitation.

I am working with the *Navjeevan Asha* project, which is one of the NGOs working in Vellore, two hours from Chennai. We have many projects all over India such as child welfare and community development projects and medical projects. In Vellore, we have launched a project called *Asha*, which means hope. The Asha project is one of the projects at the rehabilitation centre for socially handicapped women and their children.

We started work in 1994 in Suriyakulam. Suriyakulam is the red-light area of Vellore. A statistical study shows that it is one of the biggest slums in Vellore with a population of more than 3 000 people. We are working with a two-fold objective : rehabilitation of the commercial sex workers and prevention of HIV/AIDS.

Activities of the Project

Alcoholism being a major problem linked with the two others, we are also concentrating on it. The three issues of our plan of action are reinsertion of the commercial sex workers, a de-addiction programme for alcoholics and AIDS awareness for the slum dwellers in general. The principle we adopted to approach these three groups is a non-judgmental attitude, ensuring privacy to the individual, instilling confidence, recognizing the aspirations, desires and capacities of the concerned people. The ultimate goal of the project is to prevent these highly vulnerable women and their children from staying in the prostitution milieu. We try to get them out of the profession and to help them to stand on their own feet and live a respectable life with social dignity.

The difficulty in working among these groups was the resistance from the local moneylenders. In the slums in Vellore, the moneylenders lend money to the pimps to bring girls from outside. The assumption is that if these pimps were educated and rehabilitated, it would be a loss for the moneylenders. So the later resisted strongly against our project and there was also resistance from the local leaders, petty politicians and from the police, who used to receive regular bribes from the brothels. We were also threatened by the local rowdies. If we were seen talking with the girls and found taking them with us, the rowdies would follow us and create problems for our staff. The local *arrack* (distilled alcohol) sellers also posed a problem, inasmuch as we were involved in de-addiction.

The activities rely on four main aspects :

Clinical facilities: health education, health awareness programmes, sanitation, immunization, treatment and referrals.

Economic improvement: an income-generation programme to develop their economic status.

Illam : a residential place for the young girls to develop them physically, mentally and spiritually by giving vocational training.

Childrens' Home : Boys and girls are given shelter and education for the betterment of their future.

Method of research operation prior to action

Social workers are placed within the community itself to take care continuously of the community programme. Trained nurses, with the help of doctors, run the clinic.

Sociological and anthropological surveys have revealed multiple reasons for the persistence of prostitution in India. From our study, we came to know that the business is taking place mainly due to poverty and destitution. Economic precariousness coupled with the socio-cultural status of women plays a major role in proliferation of prostitution in India. Sexual slavery is prevalent in all parts of the slums in Vellore. Pimps, procurers and prostitutes were interviewed for a period of time prior to the project implantation in order to obtain their socio-demographic status and their knowledge of and attitude towards the epidemic, as well as their perception of their clients. This gave us a preliminary impulse to design proper guidelines for the coming project.

The paper I am presenting intends to give some basic information that we have collected from the CSWs with whom we are working. It is not a research work, but just provides baseline information. Here, I will concentrate mainly on the problem of prostitution, insofar as industrial sex is taking place all over the slum areas in Vellore, as well as in the central part of the city.

For a period of nearly one year we interviewed some twenty pimps and thirty girls just to obtain the social demographic status and the awareness of AIDS and their perception about their clients. The girls/women are either residents of Vellore or visitors working on contract basis.

Profile of CSWs :

Table 1 : Nature of business

Fully involved in prostitution 80%

Partial involvement 20%

The number of ladies fully involved in prostitution represents nearly 80%, while those partially involved constitute 20%. Partially involved means they just come for one week or for one day and go back to their home according to their need of money.

Table 2 Age groups :

Adolescent girls 80%

Age of 20 - 35 80%

Age of 30 - 45 11,4%

Table 3 : Religion

Hindus 88,6%

Muslims 2,8%

Christians 8,6%

Table 4 : Educational status

Illiteracy 63% Primary Education 31,4% Above 5th standard 5,6%
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Table 5 : Marital status

Married 45,7% Married with children 17,1% Unmarried 31,4% Widows 5,8%
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Table 6 : Major reasons for involvement

Socio-economic reasons 94,3% Enjoyment through the process 5,8%
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Table 7 : Knowledge of AIDS

With full knowledge 34,3% Less knowledge 62,9% Not aware at all 5,8%
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Table 8 : HIV status (blood screened for HIV)

12 girls among 35 have been screened 8 out of 4 were HIV positive(i.e. 75% HIV positive)
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Profile of clients :

Each girl will have sexual activities with ten to fifteen clients per day during first week of the month. Then she will have five to ten clients a day in the middle week. Finally the number will be reduced from three to five clients a day in the last week.

The payment by the clients varies a lot. It is in relation with the age, the complexion, the beauty and the negotiating ability either of the *broker* (*madam* or *aunty*) or of the girl.

5-10 rupees : 50% of girls involved

10-25 : 12%

25-50 : 15%

50-100 : 15%

100 & above : 8%

Age group of the clients

12-15 : 5%

15-25 : 25%

25-35 : 45%

35-45 : 10%

Above 45 : 5%

Marital status

Married client 80%

Unmarried client 20%

Reasons for visiting prostitutes

lack of privacy at home : 50%

child bearing mothers : 15%

marriage adjustment problems (non co-operative wife) 7%

Sex urge due to alcohol 3%

Sex urge due to seeing movies 2%

Others 23%

6. Social status of the clients :

Business people 7%
 Government employees 12%
 Drivers 31.2%
 Coolie workers 35%
 Students 5%
 Non workers 9%

7. Knowledge of AIDS/ condom use

with full knowledge 65%
 Less knowledge 30%
 Not aware of AIDS 5%

Profile of the epidemic

We have only little quantitative information, but it reveals a terrible situation. A sample of twenty-four young boys from the age group of 16-25 years - mainly rickshaw pullers and coolie workers - were screened for HIV. Twenty-one of them were found to be HIV-positive. Apart from this, within two years during the period 1894-96, thirteen prostitutes expired from AIDS, as well as two babies at the age of six months, two females and nine males (25-40 years of age). All in all, 75% of the vulnerable community is expected to be HIV-positive. The vulnerable community is comprised of women in prostitution, pimps and regular clients.

Actual result of the project

Better reports of CSWs/pimps awareness on HIV/ AIDS
 Improvement in social awareness in the community
 Improvement in health care
 Improvement in behaviour (less drinking and more use of condoms)
 Improvement in cleanliness personal/environment
 Improvement in educational level
 Little sustainable improvement in economic status
 Structural problems with money lenders, local policemen

Preparing children for the future

Planning for the future of children and their protection from the vicious circle of becoming a sex worker or a pimp is considered to be the most important issue. Around forty-five girls and fifteen boys belonging to the most deprived families have been rescued from their social milieu and placed in a child care home. All of them are at present school-going children, from the first up to the tenth standard.

Subsequently, in order to save the next generation, we have taken about twenty-four girls who are of children of the pimps, rowdies and prostitutes. We are giving them a proper education so that they can stand on their own feet through self-supporting complete care in the physical, mental and spiritual aspects. Afterwards, they are provided with vocational training like tailoring, industrial work. They are then placed in jobs at different places in leather factories and some girls work as domestic help. As a result, we have four pimps who came forward resigning their old occupation and who entered through our micro-enterprise development programme. They are today getting a new profession.

Suggestions and conclusions

According to our experience, the following suggestions are liable to have an impact in the war against AIDS : promoting rehabilitation home for HIV/AIDS patients, bringing out a positive behavioural change towards prevention of AIDS, developing the home-care system, enhancing the testing facilities and raising public awareness.

In order to discourage prostitution, the government should strictly enforce existing laws with severe penalties for those convicted of trafficking in prostitution. It should formulate new laws under which the clients and agents will be more punished than the girls. Institutional bodies should impart special training to police and other government personnel to sensitize them to the epidemic and the social aspect of prostitution. Above all, sex education in high-risk communities is a must.

Discussion

Ramkumar : You said 75% of the sex workers are infected with HIV and 75% of their clients are also infected. How did you work out the percentage? Did they volunteer for the test, or did you force them to undergo the test?

Alice Pushparaj : We have done a sample with the girls involved and with local rickshaw pullers. Out of the twelve girls screened for HIV, eight were found to be positive, which works out to a rate of 75%. It is a small sample but it nevertheless shows the prevalence of the epidemic. We did not force them for testing, we worked in collaboration with the Christian Medical College Hospital where they received pre-counselling. The CMC Hospital in Vellore was one of the first institution in India to provide counselling. We then let them take the test only if they were willing.

Ramkumar : Were they informed about their positive status ?

Alice Pushparaj : They were counselled and informed about their status.

Ramkumar : As far as Pondicherry is concerned, in the sentinel surveillance among the sex workers, only 6.74% were found to be HIV positive. That is why I am surprised when you mention the incidence rate of 75%. It seems unbelievable.

K. Santosh : You gave interesting information on the moneylender's nefarious activities. I know from many places I have visited in Chennai and peri-urban areas that not only do the moneylenders procure the girls and induct them into the profession, but they also manage that the sex worker already involved in the profession will not be in a position to leave it. For instance, women borrow small amounts from the moneylenders for alimentation and religious purposes and to meet other kinds of unpredictable expenses like paying the doctors when they are sick, bribing the police and sending money home in case of acute needs. The moneylenders operating around the red-light areas demand high interest rates. Until the money is repaid, the women will not be allowed to leave the area. Moneylenders have the support of the local rowdies and the police. All this microcosm works like a well operated network.

Opening Ceremony of virgin girls in Madurai city

Jaya Karuppayee, Mercy Trust, Madurai (Tamil Nadu)

I was born in Madurai and I belong to the Pramallai Kallar community. When I was young, I became involved in prostitution and then I became a broker. A few years back, I started working with Image. I was involved as a social worker. Due to my acquaintance with the milieu, we managed to identify more than 1 800 sex workers. We used to go to their place and distribute condoms and demonstrate how to use them. As a social educator, I went into the field to create awareness among the women in prostitution. After all why do they come to this profession? It is not only due to poverty and to provide money for their families. Some of them who have run away from their homes because of various reasons are also involved in this business. It is a myth to believe that a woman earns a lot in prostitution. With some notable exceptions, a woman hardly makes seventy rupees profit at the end of her day's business. When she comes to the streets she is harassed by the rowdies, the pimps and other people. There is a social stigma, and persons who have identified her will use slang names : she will be called colour TV if she is fair, and black and white TV if she is dark skinned. Women are regularly forced to give bribes to various persons : pimps, police, etc. On an average, one can say that even if she earns two hundred rupees a day, she has to spend half of it for extra expenses.

As for the intervention, since I was in this profession a few years ago it is easy for me to identify both low- and high-class brokers. I am able to interact with them and with the rowdies. Everybody knows me and I know them. As I am a part of the community, I am able to interact without danger and to get more information.

Recently, just four months back, I created Mercy Trust which was founded by the sex workers of Madurai who are still involved in the business. But because it is still a new creation, I will not speak about the purpose of this new community-based organization. I will focus on a subject of particular relevance in the time of the epidemic.

The opening ceremony

The opening ceremony (deflowering) happens two or three months after the girl attains puberty. The news is spread, either through the pimps or through other people in the community and, once a customer is available, the fees are bargained. Two years ago, in 1995, the fee was about 5 000 rupees to 10 000 rupees, but now the first person to have sex with a young fresh girl has to pay more : the rates have increased to as much as 25 000 rupees. In the morning after the first night, the girl is given a saree and blouse just as is done for a bride. Half the bargained amount is paid to the girl during the night and the rest is paid in the morning after the proof of her virginity, i.e. if blood stains are found on the bed and her clothes. Girls are made to enter into this arrangement mostly by their own parents and because of acute poverty and the impossibility to provide a dowry.

In general, the client should satisfy himself as regards the beauty, youth, structure of the body, colour, etc. All these physical features are particularly important for the engagement of a fresh girl. First, the broker will visit her house as a relative of the family to see the girl. Then the broker will make arrangements for the client to see the girl. The client will usually have to come to see the girl at the broker's place or residence. In exceptional cases, one goes to the place of the client if he is well-known and one feels entirely safe. The client will look briefly at the girl in some public places, like a temple, in front of the cinema theatre, school, or bus stop. Then according, to the time available, the client will fix a day auspicious for both parties, and the broker goes with the girl to the place of the client.

Most of the clients from Tamil Nadu would prefer to perform the opening ceremony in a traditional manner as *Santhi Muhurtham*. For the first sexual intercourse between bride and bride groom after the marriage, an auspicious night and the time are fixed by the elders of both families after consulting the Brahmin priest or astrologer. This is one of the customs practised after the marriage among Hindu families. In the same manner, the client prefers to meet the girl in the bedroom on an auspicious day fixed by the client as the first night of a bride and bridegroom after marriage.

In my life as a woman pimp, I made two very young and fresh girls enter the field of prostitution. The first experience of these two girls was different, corresponding to the different wishes of the clients who were interested in having sex with very young and fresh girls. I will now tell their stories.

Sasi

After the death of the head of her family consisting of four persons, the mother and children migrated from Karnataka to Madurai. The family was composed of a fifty year old mother, a twenty year old daughter, a fourteen year old younger daughter and a ten year old school boy. After six months, the elder daughter, called Gowri, came to my house. She sought an accommodation to do prostitution and I allowed her to join in my brothel set up. Whenever she was in need of money, she used to come to my brothel house and do her business on the basis of 30% commission for me. Whenever she was free, she talked about her family's financial situation and her wishes for the welfare of her younger sister and brother. One day she talked about the financial crisis caused by the marriage preparations of her younger sister. The money Gowri earned from the business was only sufficient for the family to live. Little by little, she sought my help to have her sister enter the business. But I completely refused to destroy and spoil her sister's life. After three months, she came to meet me along with her younger sister, namely Sasi, and convinced me to help her. Finally, I accepted to help her on condition that after the marriage, she should not do this business anymore.

I then informed the brokers about the existence of a fresh young girl and I also informed my clients, who were very important people like industrialists and rich traders who were generally interested to have sex with fresh and very young girls. These clients belong normally to the age group of 45-55. Most of the time, these clients would not want to go to a brothel to enjoy sex with the girl, but would prefer a guest house or any safe place well-known to them. I contacted a fifty year old client from Pondicherry who was well-known to me and he asked me to make arrangements for the opening ceremony. After deliberation, we decided upon a Wednesday evening, I brought Sasi to Pondicherry and sent a message to my client that I was waiting with the girl on the sea shore. At the fixed time, he came by car to the arranged place on the sea shore. Staying in the car, the client saw the girl standing and walking at a very little distance. After having watched her for five minutes, he informed me of his acceptance by means of signs and left. We then returned to Madurai and waited for the call from my client. A few days later, he called.

So I went back to Pondicherry with Sasi and stayed in the guest house arranged by the client. I organised the night according to the taste of the client. On the first night, Sasi was prepared to be beautiful. She was made to wear a costly new saree selected and bought for 3 000 rupees by Sasi according to her pleasure. She was made to be feet happy. The bed was decorated with flowers. Fruits and milk were placed near the bed as is done when a newly married couple engage for the first time in sex. My client came at the appointed time and asked me whether the heroine was feeling happy. Then he gave me 10 000 rupees as advance and entered into the room. Immediately thereafter, I sent Sasi into the room with a glass of milk. Before coming to Pondicherry for her first experience with the client, she had been well informed by her sister about the client and was instructed as to how the client would behave during that night, how to satisfy the client, how to make him feel happy. Her sister, and to some extent myself, told her as well what feelings and experiences she would have.

On the next day early in the morning, the client came out of the room and told me that Sasi co-operated with him and he was happy. He gave me the remaining 5 000 rupees as the balance and left the guest house. Two hours later we also vacated the guest house and returned to Madurai.

At that time, the rate for a fresh girl was running around 12 000 to 18 000 rupees. My client accepted Sasi for 15 000 rupees. It was usual to pay one-third or one-fourth of amount before entering the room. So the client paid 10 000 rupees before entering the room and again 5000 rupees before leaving the house. This customary precaution was followed by both parties. The client will retain one third of the total amount until the end because the brokers sometimes may cheat the client by supplying an experienced girl instead of a fresh girl who will be easily identified on the first sexual intercourse when bleeding will occur. Sometimes the client may be unsatisfied because of non-co-operation in bed. The rule is that the girl should absolutely behave as an enthusiastic bride.

I transacted directly with the client without any broker. But in most of the cases, the broker from the clients side will arrange the meeting. In such cases, we have to give 30% as his commission. On the girl's side, the broker will take 30% on the rest and the remaining will be taken by the girl. But in the case of Sasi, I took 5 000 rupees (30%) as my commission and I left 10 000 rupees for her. It may happen that after enjoyment with the little girl, clients want to give personally some tips to the girl. These tips may be in the form of jewellery, valuable objects or money. In this case, Sasi got a chain of nine grams made of gold (with a value of 3 000 rupees) as a personal gift from my client. The clients meet all the expenses from the selection of the girl to the end.

After returning to Madurai, Sasi wanted to stay with me to earn more money for her marriage. I engaged her for two years on contract with a 30% commission. For the young girl's next three encounters, she was engaged at a rate of 10 000 rupees for a night. Then she was taken by clients from 3 000 to 5 000 rupees nearly ten times. During the first three months, she was engaged at the above mentioned rates. For the next three months, she was engaged for 1000 rupees a night two times a week. Then she had contact directly with some brokers and did her business on a day-time basis. Finally, she also went for 50 rupees for a simple shot. At the end of the second year, she met a mill worker as a client who fell in love with her. After three months, the mill worker, who knew of her past life, asked her to marry him and she accepted. With the earned money, she bought a small plot and built a small house and commenced a new life with her life partner.

Sasi is now working in the same mill where her husband is working and is living peacefully. She has had no contact either with me or any other old broker known to her.

Geetha

Coming from Usilampatti, Geetha is the second daughter in her family consisting of the 45 year-old mother, an elder daughter of 14 years and a younger ten-year old daughter. A few years back, they all returned from Andhra Pradesh, where the father who had had a small business for ten years had recently died, to settle in Madurai. The family was settled on the street where I was living. Sometimes it happened that the mother met me and spoke of her inability to earn money. It also happened that I gave her or the children money. This relationship continued for six months. Once, the old lady talked about her elder daughter and asked that I introduce her into my field. As Geetha was a very little girl, I refused to give my acceptance.

In the meanwhile, every year I used to go with the girls with whom I ran my business to Thiruchendur for a week-long festival. There we had plenty of opportunities to meet pimps and brokers who also used to come for the same business. We would meet and exchange the girls who were willing to go with others. At that time, I met a broker well known to me who came from Kerala with his girls. We talked and exchanged some of the girls. After the festival, I invited him to Madurai where I returned with my "team" and the broker, who stayed for three days. At that time, the broker noticed Geetha while I was talking with her and her mother. He asked me about this fifteen year old girl who looked so fair. I explained to him her family situation and the broker asked if he could find a client interested in having sex with a virgin girl. It was decided that he would inform me and he explained how I could find his place when I came.

After one month, I received a letter from the Kerala broker and who asked as to the willingness of the girl to do the business at Kerala. I talked to Geetha's mother and left it to her to take the decision about the future life of her daughter. As she was suffering from poverty and having no other alternative to earn money, she accepted the offer. I then spoke with Geetha about life in prostitution. A few days later, when it had become clear to her what she would do, I wrote a letter to the Kerala broker informing him of our arrival at his place.

On an auspicious day (after consulting an astrologer), I journeyed with Geetha to Emakulam, in Kerala, where we stayed in the house of the broker. The next day, he introduced me to the pimp, a Muslim woman, who took charge of Geetha. I left Geetha with the Muslim woman and I returned to Madurai. One month later, I received a letter from the Kerala broker saying that Geetha refused to stay in Kerala; he urged me to come immediately. I went back to Emakulam and met Geetha, who informed me that she was still willing to enter the business, but the husband of the pimp had been trying to compel her to have sex with him; a blackmail she refused. I asked the broker about this, and he explained that situation, saying that 90 per cent of the clients in Kerala would not choose to have sex with a very young virgin girl, as they would not want to see the blood on the bed. The clients would rather have sex just after the girl's first experience, and they would be ready to pay the same amount as a Tamilian would pay for a virgin girl.

In fact, the Muslim woman had identified a client who had already come to see Geetha. The middle-age man was willing to have sex with Geetha after the bleeding. That is why the Muslim woman's husband was wanted to compel Geetha to have with him, according to the wishes of the client. I got the point and explained the situation that Geetha had misunderstood. But she replied that she had understood and that she was not mistaken: she was feared that if she had sex with the pimp's husband once, she would be obliged to have sex with him whenever he would like afterwards. This, in turn, would lead in the future to conflict and dispute between husband and wife. As an alternative solution, Geetha was willing to have sex the first time with another broker known to me. So I asked my friend the broker to accept the willingness of Geetha, and he did.

The Muslim woman then contacted the client to come on the next day. The client fixed the time in the afternoon, and at about three o'clock he came to the house where the broker, the woman pimp, Geetha and myself were waiting in the hall. In the presence of the client, my friend the broker and

Geetha went into the room for defloration. A few minutes later, the broker came out and Geetha went to have a bath for purification. Then we three persons, the client, pimp and myself, went into the room and the client verified that there was blood on the bed. As he was satisfied that Geetha was a fresh girl, he told us that he would come back the same night to engage her. As the client had arranged, he came back and spent the whole night with Geetha.

Through this story, one can see that the clients in Kerala did not give the same importance to the first night as those in Tamil Nadu. Not as much money was given to the party as in Tamil Nadu and the rate was also in comparison less. The client gave Geetha 2 000 rupees, and a saree worth 1 000 rupees as his personal gift to her and 6 000 rupees were given to the broker. Out of 6 000 rupees, the pimp took 1 800 rupees as 30% commission. A thousand rupees was given to my friend the broker. The remaining 3 200 rupees was given to Geetha. Totally on that day, she earned 3 200 rupees plus the gift of 2 000 rupees and a thousand-rupee saree. Geetha wanted to give me 2 000 rupees, but I took only 500 rupees for the expenses I had met for her. She gave me 3000 rupees give to her mother. I returned to Madurai, leaving her in Emakulam, and as promised I gave Geetha's mother the money. From that day onwards, the poverty in the family fades away.

Six months later, Geetha returned to Madurai and asked me to accommodate her in my own business. She told that she could not earn much money from the clients in Kerala. I engaged her on contract for three years on the basis of a 30% commission. I fixed the rate of 2 000 rupees for a night and from 500 to 300 for a single shot. Subsequently, under my direction, she earned much more money from the clients in Madurai and other surrounding places and I, too, earned a lot with her due to the commission. I always saw that she engaged rich men and VIPs. Once, while she was working in my team, I advised her to leave this business of prostitution and, as she was still young and beautiful, it would be better to get married to a man with a proper job. I explained that later it could be too late and that ten or fifteen years from then she would come down and again face poverty. But she was leading a good life and becoming greedy. She also replied that life now gives her much happiness and relief from her past poverty as she could buy whatever she wished and could go wherever she wanted to go. If she were to have the chance to get married to a good man who respected mankind and did not consider her past life, she definitely would. Otherwise, she would not object to living as a concubine with a married man until she met someone able to give her affection.

After the three-year contract, she left me and still continued the same business, either through direct contact or with known brokers. She has built a good house with the money she earned, and she is still beautiful. Even today, she keeps her position at the top as “ number one ” in the business. Whenever she meets me anywhere, she does not forget to give me some money with pleasure, in spite of my reluctance.

In my life, I only introduced the two young girls mentioned above to prostitution. Although a few years back I was still sometimes acting as a pimp to earn a living, I kept a promise not to introduce any innocent girl to the field of prostitution, irrespective of the reasons put forward by the parents or the girls.

Discussion

David Thiagarajan : Once I introduced Frédéric Bourdier to a girl who had been searching for a client for more than five days. For the opening ceremony of their daughter, the family was expected to get about 15 000 to 20 000 rupees. After this the family would be in position to purchase some jewellery for her wedding. Even though we gave counselling we were not able to stop this from happening.

John Dalton : **The four papers presented in the present session are burning. It proves that NGOs also know something about the field in which they are working. It shows that many NGOs are doing research along with their action.**

Prof. Gurumurthy : **We all know the people and the impressive amount of money involved in prostitution. We are aware of the social forces and the persons who encourage or force them to enter the sex trade. *Devadasi-s*, who are girls dedicated to a deity, should be virgin at the time of being dedicated. Traditionally, the temple or the temple community identifies the person who should represent the god and have sex with the girl during the ritual initiation. At that time there is a lot of bleeding. Here is an interesting fact : there is an incorrect belief in India that men suffering from an STD who have sex with a virgin girl and come in contact with her first blood will be cured of the STD; this is why men look for virgin girls.**

F. Bourdier : The same attitude is sometimes observed for HIV/AIDS, inasmuch as it is perceived as an STD. But the reasons why a middle- aged man decides to have a penetrative relation with a young girl is not restricted to the fact you mention. For instance, very schematically, an exchange of body fluids is also an exchange of blood and through a sexual relation between two partners of unequal age, there will be an exchange of vitality from the younger to the older one. This is not only a popular notion, but an idea that you will find in the classical texts of Indian medicine : blood contains the “ strength ” of the person and this substance can be transmitted between two individuals.

M. Govindan : **We are getting a little too deep into research. We need to talk about the judiciary and sex practices. While working with women in prostitution one should know the feasible and acceptable objectives : rehabilitation is fine but the Indian legal system has laws which just ban and prosecute any sex-trade activity. Making legislative changes is not an option but a necessity in the beginning. Another questionable issue : does the sex worker use condoms? We can all distribute condoms, but how many use them? Are the sex workers able to negotiate with the customers to use them? I think Mr. Thiagarajan from Image could guide us. You are distributing condoms. How many sex workers and their customers use them?**

David Thiagarajan : **Our staff is distributing condoms in brothel houses, where the majority of the condoms are consumed. We try to create awareness by showing slide shows and demonstrate condoms. But the time taken by us to do these awareness programme means, in fact, money lost for the sex workers. Consequently, we work under time constraint. As I already said, when the sex worker and her customer go to a lodge, they do not have enough time to wear a condom and the sex worker might not have time to negotiate and make the client wear one. Estimates are difficult, but I would say only about 40 to 50% of them manage to regularly use condoms in a successful way. Sometimes a girl might have sex with ten clients in a day; with six she might be able to use a condom, but with the remaining four she might have sex without a condom. At other times, the girl might be in a drunken state and might not bother to use a condom. The sex worker may ask the client to use a condom, but the client might refuse. One cannot say that condoms are being used 100%. It is highly impossible for a common prostitutes. I would think that hardly 5% of the sex workers in Madurai systematically use condoms at present. It is mostly the call girls.**

G. Gunavathy : Mr. Thiagarajan has substantiated his experience while intervening with sex workers and noted the difficulties faced. I would like Mr. Shahul Hameed, secretary of the Centre for Social Reconstruction (CSR), from Nagarcoil, in Kanniyakumari District in the extreme south of Tamil Nadu, to tell us how he managed in the field when conducting his intervention programme among commercial sex workers and among housewives having multi-partner sex.

Dr. Shahul Hameed : If an unmarried woman has a sexual partner, she keeps this a secret from society. In the case of a married woman, she has contact with somebody to have sex without the knowledge of her husband and children. A majority of them get involved in sex as a result of desire, friendship or to solve specific economic problems. In fact, the majority of the male partners have sexual contact with female partners in different places which they frequently visit for their own affairs. CSR recently conducted a survey in six villages in Kanniyakumari District. The result of the survey indicates that 60% of the women in two villages, 30% of the women in three villages and 15% in one village have multiple sex partners. These groups of women fell into the category of vegetable/fruit/flower vendors and construction workers. It was also found that the husbands of these categories of women were working, or living and working, in distant places. It was much more difficult to identify the housewives who have multiple sex partners than the full or part-time sex workers. In a particular community we observed that some males get married with women belonging to

their close relatives in order to share in the wealth of the family of the wife ; at the same time they maintain contact with another woman - whom they cannot marry (caste difference, etc.) - for their pleasure. A man may even secretly maintain another family in addition to his official family. Last year in Kanniyakumari District, there were twenty five deaths due to AIDS. More sex workers are found in a place called Villavankadu. Nearly 48% of them were infected by an STD, but in this village sex workers are not getting any regular treatment, except from traditional healers. As Jaya Karuppaye mentioned in the case of Madurai, the bulk of the sex workers do not earn much from their clients. Sometimes they are cheated by them. They do not know how to use condoms in the villages. They do not have any knowledge about STDs/HIV/AIDS. We have approached the Tamil Nadu AIDS Control Society for funds for an awareness programme project among sex workers and housewives who are ignorant about STDs/HIV/AIDS, and we have also requested permission to open a health care centre. We presently conduct two meetings every month. One is for sex workers and the other is for housewives who have multiple sexual partners. In these meetings we undertake general counselling and try to create awareness of STDs/HIV.

Usha Raghavan : How do you reach the housewives? Do they speak frankly about their multiple sex practises ? Are they open-minded enough to admit this ?

Shahul Hameed : As you know, even commercial sex workers do not frankly admit that they are practising prostitution. First, our social workers find a prostitute who is persuaded to bring at least ten sex workers to the meeting. The same strategy is adopted for housewives who have extramarital relations. We use the snow-ball methodology : whenever we identify a woman during counselling who engages in multiple sex practises, we suggest that she give information to others, either directly or indirectly through us whenever possible.

Usha Raghavan : You said that 60% of the women in two villages have multiple sexual partners. How did you arrive at this figure?

Shahul Hameed : When I saw the report of CSR in which the above- mentioned figures were given, I could not believe it. I then selected that area for my project. I faced many difficulties for three months, even in identifying the commercial sex workers. And then I found a part-time commercial sex worker with the help of a person known to me. I convinced her to co-operate with me, and with her collaboration, I undertook a secret survey by means of a questionnaire to one hundred women. These questionnaires were distributed Among the housewives, which they were asked to complete, without mentioning name and address. This gave them courage to fill in. When answering the question regarding the number of persons contacted to have sex, many respondents indicated the column two to five. Afterwards, during the counselling, they again revealed that they still have sexual contact with one or two persons apart from their husbands. Some had sex for money to meet unexpected expenses and some had sex with others either for pleasure or for getting extra money.

Usha Raghavan : How did you differentiate women who had sex for money and those who have sex for pleasure?

Shahul Hameed : During the counselling, they revealed that they had sex with others out of friendship. After having sex, they never asked money. When the woman wants money, the regular sexual partner fulfils her wants. It was not counted as the sale of sex. On the other hand, some women had sex with regular sexual partners for money to improve their households or to have additional income. They may also be recompensed in kind (sarees, gifts, etc.)

Dr. P.K. Das : At present, NGOs are working on intervention programmes for sex workers. The question of sustainability also arises. Voluntary organizations argue in general that the community itself will take over their problems in the future. How far is this in fact possible in your area of concern and from your experience?

Shahul Hameed : At present, we are making them feel the need to create self-help groups. This implies dedicated persons, who should have qualities of leadership, acting as peer educators. We as an NGO may intervene in the process, but only to a limited extent because they have to learn by themselves. Somebody in a group will definitely have capabilities. For these persons, we provide training and explain to them how to put the strategies into practice. Further, we also educate sex workers. One example : instead of having sex immediately, some clients prefer to spend some time talking. During the conversation, the sex worker should talk with the client about the benefit of condom usage. Although the client may reply that it stands in the way of natural pleasure, it is better to insist upon its use and show the client that, for instance, if the woman puts it on him it can be enjoyable. In case the woman feels that the client suspects her health condition, she should continue her conversation and offer the client without penetration if he is strongly opposed to the using a condom. In other cases, the client may agree to have penetrative sex with a condom at the first encounter, but the second time with the same woman he may try to have sex without. Then she has to be able to turn him down.

Man respondent : One thing is to be stated : the commercial sex workers are not alone responsible for the spread of AIDS. It is better to educate the new generations and to prevent them from entering into commercial sex. Shahul Hameed intervention is focused mainly on women having multipartner sex and it is not restricted to sex workers. From the experience obtained, it has to be noted that identifying a sex worker is easier than identifying the housewives and men who have multipartner sexual behaviour. However, the intervention programmes should reach these persons which, in fact, constitute a majority of the Indian population.

Usha Raghavan : The Tamil Nadu AIDS Control Society, UNAIDS and other funding agencies with the collaboration of NGOs have sufficiently created awareness of AIDS in general throughout India through all types of media. Still, many NGOs submit the same guidelines and targets for their projects. They have to come forward with new strategies from different aspects. At present, all funding agencies have some fixed target groups they have selected for various reasons. The fact is that they invite NGOs to work on the proposed targeted groups with them. Here again, NGOs should co-operate and collaborate among themselves to exchange information obtained from the field. The relevance of the present seminar in that aspect is also obvious.

Shahul Hameed : I clearly stated in my lecture that I did not work on commercial sex workers. We are conducting quiz programmes on AIDS for selected youths and we are also educating the general population of women through women's associations. We work according to the demand of the government.

Man respondent : It may be useful to work with the people who have a high rate of sexual partners. They constitute a group which has much influence on the epidemic in society. But the objective is not only awareness among the general population, the objective should be to promote sustainable behavioural change. Just creating awareness without behavioural change will not prevent the epidemic. As you noted, interpersonal counselling and forming women's self-help groups will be effective in reaching the ultimate goal.

S. Shekar : NGOs and community-based organizations should also work among police constables. Many sex workers, either men or women, complain that rowdies and police people are involved indirectly and are also preventing under law the sex workers from exercising their profession, while at the same time they themselves are involved with sex workers. Therefore, they should also be considered as a target population.

Draviam : We have to consider how far we are involved with police, rowdies and clients. The target group is only CSWs. Their clients and police people are related to CSWs by trade and law respectively. All are included in the objective directly or indirectly. If we avoid the available victims, we are considered to lack the boldness or the courage to face or to venture into the field. Taking into consideration the other side will also lead to a more successful work.

Usha Raghavan : Nobody objects your point of view. Clients belong to the general population or to any other targeted groups. But the funding agencies require some guidelines from the NGOs.

Draviam : As you are the representative of one of the funding agencies, why do you not find the strategies to work with the clients when you find so many reasons to target CSWs ? When we are able to find the housewives who practise multiple sex, it should become easier to identify the clients and to consider them as a target group.

Usha Raghavan : The general population has been covered directly or indirectly in various sectors, like industrial workers, construction workers, business people, etc., in which clients can be found. One can say that it may be done separately, or all of them together. Further, the funding agencies have got their own limitations and all funding agencies have their own criticism of NGOs regarding who they are targeting and how.

Dr. Bobby Zachariah : In our association in Maharashtra, we are not targeting only CSWs, as they are not basically important, contrary to what common sense would have. The most important and tautological point is that clients may come under the general population. It is also not deniable that generally our approach starts from the general population. For example, in Uganda, the community people have gone in teams from door to door and spoken with both males and females. The family members have become much more aware of HIV/AIDS. So we need to prepare or to organize in a similar way to create a greater awareness of HIV/AIDS. In some places, the people from the community have already started to work on this basis. Now the role of NGOs is to encourage the community people who are ready to act on this basis.

F. Bourdier : Condom vending machines have been installed in selected areas like bus stands and railway junctions in important cities and towns of Tamil Nadu. Are clients benefiting from what we can call innovative technology ? What are the attitudes of clients towards the availability of condoms through the condom distributing machines? David Thiagarajan was the first person to implement these machines in Madurai : what happened after a couple of months ?

David Thiagarajan : It was a complete failure. In Madurai, machines were installed at high cost by a company from another state. No local technicians were trained to repair them in case of problems. And the machines were soon broken everywhere. This is not an adequate solution to facilitate condom distribution.

HIV Interventions for Drug Users

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Introduction

Injecting drug users have become a significant risk group for the human immune deficiency virus (HIV) and now play a major role in HIV transmission in many parts of the world. Injecting drug abuse is escalating in India and injecting drug users are found in all major metropolitan cities of the country. The injecting heroin users in Northeast India have been greatly affected by the HIV epidemic (Naik et al, 1991) and in one year the HIV infection escalated from 0% to 50%. Easy availability of injectable preparations like buprenorphine has resulted in many injecting buprenorphine users in different places like Calcutta, Chandigarh, Madras (Kumar et al, 1995a), Cochin and various other places. Compared to studies and services for other groups at increased risk for HIV infection, there has been little research and few programmes for IV drug users and the prevention efforts at HIV risk reduction have been greatly neglected in India. Since there is a great potential for the rapid transmission of HIV infection among injecting drug users, there is an urgent need to design, implement and evaluate HIV interventions for them. In this paper an attempt is made to outline the various HIV interventions that have been found to be successful in many places.

Drug abuse treatment

Many believe that providing treatment for drug users is the primary strategy for preventing HIV/AIDS among them. This strategy is strongly recommended by the National Institute of Drug Abuse. Studies have reported a negative association between early entry and retention in methadone maintenance treatment and HIV exposure (Abdul-Quader et al, 1987). In spite of the evidence of the effectiveness of methadone treatment in reducing HIV risk among drug users, methadone is not available for drug users in India. It is paradoxical that methadone was available in this country when heroin use was not seen visibly, but at a time when the country is facing a huge heroin problem, methadone is not available. Also the professionals dealing with substance abuse treatment have not been vocal in advocating the availability of methadone. Although sublingual buprenorphine has been tried in New Delhi as substitution treatment for heroin users, the evaluation of these programmes has not yet been published or made known. Also buprenorphine abuse is very prevalent among former heroin users and injection buprenorphine has served as a transition from pills to injecting for many opiate users. The drug abuse treatment is also complicated by many issues apart from the non-availability of methadone. Entry into treatment is not likely to be sufficient, but the critical factor is retaining the person in treatment. Since most treatment centres in the country provide a short-term treatment (detoxification only) with no or only inadequate follow-up, the chances of retaining clients in treatment are bleak. A study done in Madras revealed that a majority of heroin addicts who underwent detoxification at a de-addiction centre relapsed within the first six months following discharge. Thus the public health utility of drug abuse treatment as AIDS prevention may require the following: making methadone available for treatment and maintenance; rapid, large-scale expansion of comprehensive drug abuse treatment. The Government's efforts at creating detoxification facilities at all medical colleges and district hospitals will probably not be sufficient as an AIDS prevention strategy. In addition to significant monetary resources, creating comprehensive treatment services would require the location of programme sites, and the selection and training of new staff, as well as taking measures to prevent staff burn-out due to the extra stresses involved in working with AIDS and AIDS prevention in drug abuse treatment programmes. Hence, it becomes important to consider methods other than the ideal by way of providing drug abuse treatment for drug users as a means of HIV risk reduction among them.

Community outreach

Drug users are a "hidden" population and a majority of drug users are not in any treatment programme. As discussed above, it is not practical to organize large-scale comprehensive drug abuse treatment programmes. An approach that identifies groups at risk of established high-risk behaviour and has strategies to influence the course of drug taking behaviour has to be considered. The approach suggested is "outreach". Outreach activities for HIV prevention are community-based and aim to facilitate improvement in health and reduction in risk of HIV transmission for individuals and groups not effectively reached through existing services. Outreach was conceived as a means to reach out to people within their own communities or local milieu, outside of the usual service settings. Outreach is important because office-based drug services alone constitute an inadequate base for HIV

prevention. People at risk may be out of contact because services are geographically or psychologically inaccessible, because they fear the consequences of contact, because they do not want to help or do not perceive that they need it, because the services are irrelevant to their needs, because they are marginalized by their life styles, or because services are not pro-active in seeking clients (Power et al, 1993). Outreach has developed in many countries like the United Kingdom, Australia, the Netherlands and the United States, and is being introduced to India (Sarkar et al, 1993; Kumar & Daniels, 1994). Ongoing evaluation of outreach projects in the US indicates that they help drug injectors reduce risk behaviour (Booth & Wiebel, 1992) and are associated with reduced seroconversion to HIV (Wiebel et al, 1993). Community outreach appears promising in Indian settings and the success of other community-based health programmes in India is a source of encouragement and guidance. And for a country encumbered with significant problems in resource allocation, outreach might provide an efficient answer. In Madras, outreach activities have been successfully organized for drug users in two geographical locations with the help of the Catholic Church and supported by Caritas India. Apart from professional social workers, former recovering drug users are employed as outreach workers. The impact of outreach strategies has been systematically evaluated and a comparative study of drug users from outreach locations and drug users from locations where outreach is not in place was done using a longitudinal study design. Baseline assessment was done for 250 drug users from outreach locations, and 150 drug users from other locations completed the baseline assessment. After 18 months, 161 drug users from outreach locations were available for follow-up and 86 were available in the other locations. There was a significant reduction in the injection risk behaviour among those participating in the outreach activities, but not in the sexual risk behaviour (Kumar et al, 1997). Thus outreach seems to be helpful in changing the injection risk behaviour but not sexual risk behaviour, and new strategies have to be developed to reduce the sexual risk and to sustain the injection risk reduction behaviour among drug users.

Needle exchange programme

Another important strategy is to provide safer injection for injecting drug users who are likely to continue injection. Drug users who do not wish to enter treatment or for whom currently available treatment methods are not effective would constitute the target group. Needle exchange programmes have had a sufficiently long history in many places around the world, in particular, Western Europe and Australia, and these programmes have been largely patronized by drug users and have a positive impact on HIV risk reduction behaviour. Data is available from the US indicating the efficacy of needle exchange programmes (Vlahov, 1997). In spite of a large amount of evidence in support of needle exchange programmes facilitating risk reduction behaviour, political support for such programmes is not easy to obtain in many places, including India. This is based on unfounded fears like increase in new injectors at needle exchange sites. The National AIDS Control Organization (NACO), India, does not approve of needle exchange, and syringe exchange was instituted on an experimental basis in Madras; its impact was evaluated in a longitudinal cohort design. A sample of 125 injecting drug users from the needle site and 125 injecting drug users from the site were recruited for a baseline assessment and followed up for 12 months. At the twelve-month follow-up assessment, there was a significant reduction in both injecting and sexual risk behaviour among those participating in the needle exchange (Kumar & Daniels, 1995). The drug users received a better outreach contact and better education about HIV issues at the needle exchange sites; this probably helped them to modify their sexual risk behaviour, too. The success of the needle exchange programme, as well as the positive attitude of the community towards the programme makes the case for its adoption in various settings in India. Such programmes are now being carried out actively in Calcutta and Manipur.

Network intervention

The fact that injecting drug users operate within diverse networks with variable hierarchies suggests that networks are an important focus for research and intervention. Studies have reported that social networks of IDUs seem to be a strong factor in reinforcing the general drug-using lifestyle. The influence of friends has been found to affect drug- and health-related behaviour, including drug injection behaviour (Friedman et al, 1987), needle sharing behaviour, condom use and rates of HIV infection among IDUs. There are some studies on the relation between HIV risk behaviour and personal network characteristics. The size and extent to which drug use and sexual contact networks overlap are characteristics usually related to the spread of HIV. The density versus openness of IDU networks is also important for understanding risk reduction. Dense networks exert considerable pressure for understanding risk reduction, and on members to follow normative defined patterns of behaviour. Depending on the degree to which values within the network concur with those of the professional helping system, this may serve to increase or decrease the likelihood of members implementing recommended risk-reduction behaviour. Network density may be especially significant for individuals without the communication skills, status, or self-confidence to join alternative social groups. For these vulnerable individuals, dense networks may act to screen outside advice and information and make the individual dependent upon the established network hierarchy. That means, if key network leaders act to lower their risk, then norms may change to make it necessary for all members to change.

Personal network-oriented intervention was carried out in Madras, based on the model developed in Baltimore, SAFE study (Latkin et al, 1995). In this model, drug users were recruited if they were willing to allow intervention in their drug-using networks. They were randomly assigned to either an intervention group or a control group. For the intervention to be successful, at least half of the identified network members have to be present in the intervention sessions and they must have attended at least three of the six sessions of intervention. A total of 36 completed the intervention sessions and they were compared with the 61 controls. At the baseline, there was no difference between the two groups for HIV risk behaviour; at the six-month follow-up, the intervention group demonstrated a significant risk reduction (Kumar et al, 1997). Since network intervention is likely to sustain the risk-reduction behaviour, more efforts should be made towards implementing network intervention. Efforts must be made to mobilize subcultural change and community development (Friedman, 1993; Friedman et al, 1993).

Drug users' organization

Gay men and lesbians were the first ones to set up intensive self-help organizations to fight against AIDS. Drug injectors have had a very different organizational infrastructure from gays. Prior to the AIDS epidemic, there were sizeable drug users' organizations only in the Netherlands. Currently, drug users' organizations are emerging as important players in the fight against AIDS. Drug users' organizations have engaged in a number of activities, including outreach activities, distribution of risk-reduction supplies, dissemination through newsletters and caring for the sick. The success of the efforts are dependent on the general social climate, whether it is hostile towards such organization, on the level of police suppression of drug users' activities, on users' accessibility to resources, on the size of the local drug users community and on the strategies of the drug users' organizations. There are no formal studies of the impact of drug users' organizations on risk behaviours of local drug-injecting communities and networks. The Drug Users' Organization has been initiated in New Delhi and efforts are being made to organize IDUs in Madras.

Problems and barriers

Translating the research findings into practical programmes is not very easy. In spite of evidence, there may be resistance to certain programmes like methadone maintenance and needle exchange. Influencing policy-makers to have programmes which are driven by science rather than by ideology is not an easy task. It is critical to understand the difficulties involved in implementation in order to overcome them and to make the programmes meaningful and effective. Many problems and obstacles are faced during the HIV intervention implementation in Madras. The problem of injecting drug use is not a priority area for AIDS intervention and the focus is only on heterosexual transmission and targets are commercial sex workers and long-distance truck drivers. Many agencies involved with drug abuse do not consider HIV intervention as an urgent issue; this problem has been overcome mainly due to the formation of an umbrella organization called Society for Prevention, Research and Education on Alcohol and Drugs (SPREAD). Having brought all the drug agencies under one roof, the registered body focuses on issues of consensus, and this body's important function to educate all the agencies about the significance and urgency of HIV risk reduction. A newsletter is sent to all agencies detailing harm-reduction strategies for drug users. There was initial resistance to the HIV intervention efforts in the community, which was overcome by the formation of a community advisory board comprised of locally influential opinion leaders. All the proposed intervention efforts were discussed at the advisory group meeting and endorsed by the board before being implemented. Addicts were generally identified by the police if they were in possession of a syringe and this led drug users to not carry a personal syringe when they went out in search for the drug. This compelled sharing practices at places outside of their houses and, in particular, at dealers' places. This was brought to the notice of the advisory board and the issue was taken up with the police officers and local police stations; it was ensured that addicts would not be harassed if they were in possession of personal syringes. This has facilitated the carrying of personal syringes by the users in the community. The funding for the interventions is almost non-existent and SAHAI Trust, the only organization involved with HIV intervention for drug users in the community, is carrying on the interventions with the support of Caritas Netherlands through Caritas India and human resources help from former users. The outreach is at present facilitating the community empowerment and drug users are learning to organize themselves and advocate their rights, resulting in community change. One of the areas on which we need to concentrate is the reduction of sexual risk behaviour. There is a large group of buprenorphine injectors in Madras and this group has a different risk behaviour than heroin injectors and hence may require different intervention strategies (Kumar et al, 1995b; Shakuntala & Kumar, 1996). The easy availability of injectable preparations like buprenorphine, diazepam, promethazine and chlorpheniramine maleate (Avil) has significantly contributed to the prevalence of injecting in Madras. Many drug users prefer a combination of the above drugs popularly referred to as CAT (Clampse - Diazepam, Avil and Tidigescic-Buprenorphine), and there is an urgent need for rigorous control measures in the city of Madras. The outreach workers are pressurized to help with the medical problems of injecting drug users, and strengthening primary medical care is an important concern in the near future. A primary care facility has been established at the field station and a primary care physician has been recruited to take care of the medical

needs of the drug users in the community. There is an urgent need to improve and expand testing and counselling facilities. Our outcome evaluation is extremely limited by the absence of sero data, even though self-reported behaviour changes have been reported in the literature to be reliable and valid measures. At present, attempts are made to counsel and test all the recruited individuals for HIV intervention, and future outcome studies will certainly use the sero data as an outcome measure. Network intervention is probably the intervention our financially constrained services can take up and pursue in the times ahead to influence the HIV risk behaviour of injecting drug users.

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Discussion

F. Bourdier : The question of injected drugs in Tamil Nadu seems to be more alarming than has been said up to now. It is surprising to hear that whenever you mention this issue in the state, officials as well as the so-called informed population tend to argue that the problem is in the north-eastern part of the country and not here. Father Daniel's research and intervention provide a completely opposed view. We would like you to develop some recent facts along with the problems you have faced. It seems that prevention among drug users has been weak. Do they consider themselves as a community at risk and are they particularly vulnerable according to your investigations ?

Fr. Daniel : First, one of the activities of SAHAI Trust is effectively focusing on injecting drug users and the people living with the HIV problem in northern and central areas of Chennai where the fishermen community is a majority. In these areas, TTJC injections (an amphetamine) are very familiar among the poor people injecting themselves. Normally the cost of it is around eight rupees. But they buy it on the black market for forty rupees. As they pay more for this, the same needle is used several times. About 186 blood samples were taken over a period of six months and we found that the prevalence extended from 4% to 19.8% according to different locations. Apart from this, the fishermen community faced thirteen deaths because of alcohol during this period. Though primary care centres exist in these areas, no one goes there for the treatment. So we gathered all drug users. We made them feel the importance of self-help groups in the community. As a result, they started a self- help group, by providing their own resources through a self-help financing scheme. We educated them on the risk of sharing the needle and counselled them. We have brought them to go for treatment in the health care centre. We have also conducted a rehabilitation programme and a vocational rehabilitation programme through which we trained them and provided job opportunities in their community itself. We got the whole community participate in the process of intervention and we could mobilize support from one community to another. Such an intervention could be a model to be replicated elsewhere. Then we have investigated in-depth individual case studies and compared with other ones. For instance we compared case A with case B and case C with case D. We found that they were similar to each other. This mapping of case studies helped us to understand how the HIV virus would spread from one community to the next and from one place to another. We could thus set up our research and training centre with the documentation programme. We have compiled a research monograph on drug abuse and HIV/AIDS. A handbook has come out. It is called " Training Manual and HIV/AIDS for the health care workers in the community ". But with reference to our research work, the risk of HIV/AIDS infection is greater than the drug injection problem. Hence, sexual behaviour should be compared with those who belong to the drug injecting group. It is worth mentioning that no funding agency grants funds in regard to injecting drug users to any NGO working in the field of HIV/AIDS prevention. The funding agency behaviour is to be changed. But when asked why, they state as a major reason that there is no such problem of injecting drug users in Chennai as exists in the north-eastern part of India. Many injecting drug users who have been infected by HIV/AIDS are of the opinion that instead of changing their behaviour, they would like to enjoy the rest of their life as they are going to die soon. They think like this because there is a lack of adequate treatment facilities. No government hospital admits them easily for treatment. And whenever some aged drug users come forward, doctors automatically reject them.

Man respondent : How can you say there should be a sort of compromise between the law and the use of drugs ? Generally, the use of drugs is forbidden by law. And you are promoting programmes for needle exchange. Does it mean that you are promoting the use of drugs ?

Fr. Daniel : Today in our country, the needle exchange programmes have not yet been officially permitted. That is why we have formed an advisory committee in the community. We had a process of educating them, as I said, with the support of the community on an *experimental* basis. We are in need of pilot studies of needle exchange. The purpose is not to promote the use of needles but to reduce the harm. The objective is risk reduction. And to reduce the risk we have implemented such programmes on an experimental basis.

Usha Raghavan : Everybody is criticising the fact that the needle exchange programme is promoting use of drugs. But it is to change the behaviour and not to promote it.

Man respondent : In our centre, we have both alcohol and drug dependent patients. So a study is needed on people contracting HIV/AIDS through needles. We have done regular awareness programmes and counselling for all of our clients for the past three years. We do regular testing for all

clients every three months. We found from our treatment that the people who are HIV-positive constitute a more prominent category than the drug dependants who used to have sex after having injected drugs. What we found is that the rate of contracting HIV through needles (transfusion, drug therapy, etc.) is higher than the rate of HIV due to the use of injected drugs (heroin, etc.).

F. Bourdier : I would like to have an internal point of view by someone who has experienced such a programme. Momoi Tonsing, what do you think about the relevance of this programme? Do you think it can work, or not?

Momoi Tonsing : I feel it is irrelevant. It has been happening for sometimes in Manipur, at Sangpur. Some people were much more encouraged in the use of drugs afterwards.

Fr. Daniel : Maybe the sociocultural context is not the same and it can be dangerous to make any generalization. I want to add, however, that whatever the importance of drugs, other problems have to be taken into account at present. First, we need to focus on child prostitution. Today, after Goa, Mahabalipuram, located on the coast near Chennai, is a tourist place where child prostitution is rampant. The Mafia operating there may have connections in the near future with Pondicherry, which is another growing place for child prostitution. Therefore, we need to wake up to this reality and see how we can best plan for the prevention of child prostitution and children being infected by HIV/AIDS. Because, until now, only a small percentage has been focused upon street children. Today it has been becoming a major problem both in the rural and urban settings. Next, there is no clear-cut idea or understanding in regard to the implementation of the law on the NDPS Act and HIV/AIDS status. In Manipur, some elites are thinking that the best way of preventing and checking the further spread of HIV/AIDS is to isolate the HIV- positive addicts and, as Momoi Tonsing related yesterday, they are locked up in jail. According to the statistics, 51% of the inmates in prison are positive. Therefore it is important for the NGOs to focus on such legal aspects. If the existing NGOs who are now facing these problems think and try to do something in an alternative way, the followers in the future may take steps in the right direction. But one has to start. As far as the funding is concerned, NGOs are trying to get funds from abroad on the basis of NGOs proving the support of the community. But NGOs are facing many problems during the process. In such a situation, the policy planners have to identify the genuine needs of the community. Finally, in the Indian context, in regard to the termination of children of HIV patients, people are more and more looking for spiritual support and care. So I do think this needs a lot of attention.

A brief paper about the activities performed in the remote area of Bangalore South District

Sr. Elise Mary, Nava Jeevan Centre, Bangalore (Karnataka)

The population upon which we focus

The population upon which we are focusing belongs to the twenty villages of Bangalore South District comprising roughly 16 000 people. These villages are very backward and located in draught stricken zones. The level of backwardness may be judged from the economic indicators available, and particularly from the fact that the per capita income of the population works out to be about 700 rupees, which is the lowest in the entire state of Karnataka. The IMR (infant mortality rate) is 127 per thousand.

As the airport is about eleven kilometres away from these villages, some rich people and foreigners occasionally visit the area. There are a number of women and young girls who work as CSWs and call girls, and there are a few houses in which this trade is being carried out. A few known brokers and pimps bring in foreigners and visitors.

Government institutions and other public bodies

There is a primary health centre located about eight kilometres from these villages. Although there is a medical officer, the facilities of this centre are not utilized by the rural poor. As regards AIDS, nothing has been done so far.

The district Health Hospital is about twenty-five kilometres away, in the heart of the city. The rural poor find it hard to obtain access to it. Although there is a wing set apart for HIV, it is not functioning properly.

The funding agencies and other NGOs

We are the only agency working for community health in this area. We receive funds from one agency, but that is not sufficient to give a comprehensive awareness and preventive programme on HIV.

There are no other NGOs working in the community health programme, although one can find NGOs involved in de-addiction work, prison, an old-age home and the care of HIV-positive persons.

Other groups and bodies

We have presently organized women in the “*Mahila Samaja*” and self-help group. In addition, we have organized youth in the villages. Apart from these activities, no other groups or bodies are present.

Our involvement

In fact, through this community health and women's development programme, we try to collaborate in a network with other NGOs of Bangalore in the field of community health and development. As regards HIV/AIDS, our involvement consists in active participation in the seminars and workshops conducted by the Indian Society of Health Administrators (ISHA), St. John Medical College Hospital, Samraksha. As I am a public health person, I am interested in the promotion of health and the prevention of AIDS. I read a lot of articles on this subject. Occasionally, we conduct awareness programmes at the grass roots level in the villages and for middle-level health workers on HIV/AIDS. Though these villages are prone to HIV, people are not taking any preventive actions. There is also a tendency to view this infection as a curse from God. As these people are illiterate and superstitious, they go to village quacks and magicians. There are no diagnostic facilities in these villages and the villagers do not usually go to

city hospitals. Recently, we have noticed that there is an increase in the death rate of those who are between the age of 20-30 years due to chronic diarrhoea, cough, fever and also some skin lesions.

We have also noticed that the people have some wrong information with regard to the transmission of HIV. For example, they believe that it is spread through mosquitoes and flies, cooking utensils, public toilets, swimming in the same pond and through casual contacts. They say that it is not spread through sexual promiscuity.

We, therefore, try to teach the people through individual, group and mass education that HIV is transmitted through sexual promiscuity (both homosexual and heterosexual), through blood and blood products and vertical transmission.

Samraksha

Nagaraj, research fellow, Samraksha, Bangalore (Karnataka)

Samuha is a non-governmental organization with a range of projects. Since its inception in 1986, its primary focus has been on developmental work and its primary area of work has been in Raichur district. Samraksha was initiated by Samuha in December 1993 to combat the growing HIV epidemic. The dual objectives of this project are:

- to control and contain the spread of HIV infection ;
- to provide counselling and support to those already infected.

Bangalore city has been the initial operational area, and work in Raichur district has evolved as a separate project due to its different needs.

Samraksha's primary focus is on offering counselling and support to HIV-positive people and their families. This involves contact with the person from the point of his or her taking the test, through his/her diagnosis of HIV-positive status and through asymptomatic stages. Besides emotional support, we also offer other support in terms of advocacy against discrimination, free medical consultations, help with placement of children orphaned by the illness, etc. Samraksha's intervention focus has also been to initiate information and preventive counselling service. These services operate from an information and counselling centre. In addition, these services are available at the following points :

- the TB Sanatorium ;
- the STD clinic at Victoria Hospital ;
- the STD clinic at Bowring and Lady Curzon Hospital ;
- the State Home for Women.

Samraksha is also involved with a programme for the protection of sex workers in Bangalore city. The main activities associated with the programme are intensive educational work with women sex workers, backed up with condom distribution and STD clinic reference. This is one of the most challenging programmes because the scenario of sex workers in Bangalore is very complex. There is no red-light area. The women are a hidden population, scattered all over the city in innumerable small groups of three or four. There is no informal or underground network connecting them. We reach them through various networks of clients, pimps and the women themselves.

At this point of time, Samraksha is also able to offer a weekly STD consultancy, free of cost, at the counselling centre for those reluctant to avail of services at the government hospital for reasons of confidentiality. Samraksha is also reaching out to men who have sex with men and with the *Hijra-s* (*Ali-s in the south*) community with information on STDs/HIV/AIDS, methods of prevention, condoms and referrals.

We are also aware that the clients of sex workers are really the consumers in condom promotion and also the decision makers. If safer sex practices are to become reality, we really need to target this elusive and invisible population. We are doing this by organizing a series of street plays at busy market places, bus stands, railway stations and other public places with the help of professional / volunteer drama troupes consisting of volunteers from youth hostels.

Samraksha is also involved with thrice-weekly educational programmes on HIV/AIDS for the undertrials at the Bangalore Central Jail.

We are also participating in educational programmes at the request of other agencies or as a support to existing programmes. This would include workshops with all levels of police officers with the specific agenda of sensitizing them to the issues involved in HIV/AIDS and the futility of mandatory testing, repressive raids and punishment as strategies in dealing with this illness.

Samraksha set up a Well Women clinic in response to identified reproductive health needs of women. Since many women, for various reasons, do not seek help for genital and reproductive tract problems, this clinic encourages women to come for examination without having to admit to a problem and aims at reducing women's vulnerability to STDs and HIV infection and early detection of cervix and breast cancer. It also provides preventive service, offering routine examinations, as well as providing medication and health education twice a week. This is run by women, providing free services and maintaining strict confidentiality.

Samraksha has started a Respite Home - temporary care for people living with AIDS. These people are those with no social support and who have no access to other care infrastructures. The Respite Home would provide nursing care for people living with HIV/AIDS and palliative care for the terminally ill. The Respite Home will provide temporary residential care which will include easy access to medication, treatment and counselling.

An overview of the awareness and education programmes

Awareness programme

The activities involved are mobile awareness, street plays, TV loops, messages and jingles.

The objective is to provide sensitive information on HIV leading to safe sexual behaviour. The needs are :

- The uneducated and nomadic people who are prone to be more vulnerable ;
- To give effective information to the whole society ;
- To educate people all over Karnataka, especially in villages, about the modes of HIV/AIDS transmission and the services provided by Samraksha.

The approach will take advantage of :

- The use of decorated umbrellas and megaphones, with posters displayed, condoms and pamphlets distributed at market places and other highly populated areas, where information is provided by a male and a female staff member ;
- The people through street plays ;
- HIV/AIDS messages by religious and popular people to be flashed on TV to effectively fight against HIV/AIDS ;
- Publicizing HIV transmission through paintings on autos, lorries, buses and vans.
- Attractive and melodious songs have been recorded to give messages on HIV/AIDS through sound media.

Educational programme

The activities involved :

- Education sessions for vulnerable groups :

- a) prison inmates
- b) construction workers
- c) youth hostels
- d) garment factories and tailoring units
- e) other NGOs

The need:

a) for the prison programme

The educational sessions are conducted for convicts and undertrials who are at risk of being involved in homosexual activities, and are thus most vulnerable to the spread of HIV/AIDS and STDs.

b) *for construction workers*

Ninety per cent of the construction workers are uneducated and mostly nomadic and lack exposure to mass media. There are chances/possibilities of sexual exposure.

c) *for youth hostels*

The youth are away from home most of the time. They therefore lack guidance, and there are possibilities of them getting involved in drug abuse and unsafe sex/multiple sex.

d) *for workers in garment factories / tailoring units*

Women are biologically more vulnerable to infection by HIV/AIDS and STDs. Most of them are teenagers and lack exposure to mass media.

The strategy of approach depends on the four situations :

a) Educational sessions are conducted thrice-weekly for undertrials at the Bangalore Central Jail, using flip-charts and posters ;

b) Programmes are conducted with the help of flip-charts and leaflets ;

c) Hostels are identified and permission sought from hostel management to conduct programmes.

- questionnaires are distributed before the session in order to ascertain the degree of knowledge of HIV/AIDS ;

- education with the help of flip-charts and slides ;

- evaluation is conducted.

d) Education using flip-charts and leaflets both on HIV/AIDS and STDs and concerning the reproductive health of women.

HIV to General Health: A Shift in Profile Experiences on Truckers' Intervention Programmes

Majumdar, A., Rao, A. et al., Bhorukha Public Welfare Trust, Calcutta (West Bengal)

In 1993, Bhorukha Public Welfare Trust (BPWT) conducted an HIV prevalence study among the truck drivers and their helpers passing through Ulubaria, a checkpoint town in West Bengal. Surprisingly, it was found that HIV prevalence is as high as 7 per cent among the truckers; hardly any trucker was found who had not visited a commercial sex worker on the highway. The percentage of truckers regularly visiting CSWs on the highway or in the city brothels was 97 per cent in the sample. This revelation came as a serious concern to the trucking industry and an urgent and immediate need for intervention was felt.

For the last four years, BPWT has been working towards a reduction of STD prevalence and the prevention of HIV/AIDS among truck drivers and their helpers from its clinic-based intervention centres at Calcutta Port Trust, Petrapole (Indo-Bangladesh border), Ichchapuram (a shipment town in Andhra Pradesh) and at Raxaul (an Indo-Nepal border town in the state of Bihar). Activities of BPWT involve targeted communication, social marketing of condoms and treatment of general and sexually transmitted diseases.

A difficult part of the project is to inculcate a change in behaviour on the part of the target population. Mere awareness does not lead to sustained change in behaviour. Messages need to be carefully selected and reinforced through repeated interventions. Records show that only 25 to 30 per cent of those who attend the intervention centres are repeat visitors.

We observe that the truckers are quite open about their sexual practices, implying a low cultural restriction on promiscuity. It is true that, owing to their profession, their lifestyles make them highly vulnerable. We also observe an increasing trend in self-perception of risk among the truckers as a result of efforts to increase awareness by many NGOs across the country. However, a fear psychosis is also generated and they resent being labelled as a community group practising high-risk behaviour.

Treatment-seeking behaviour is very low among the truckers. They prefer to remain untreated, unless compelled by the severity of the disease. Visiting quacks and *jaribootiwalla*-s is still very prevalent among them. Our clinic records show a variety of other diseases among the truckers - cough and cold, fever, chronic gastritis, worm infection, diarrhoea, bronchial and respiratory track infection, throat and dental problems and various types of skin diseases. They attend little to their personal hygiene and have little concern for the health of their wives. STDs are transmitted to their wives, who become a source of further infection for the truckers themselves if they remain untreated. Openness about sex, sexuality and health as a whole, is almost absent from families of truckers, which are harsh and male dominated.

In order to make STD treatment more acceptable to the truckers, STD/HIV/AIDS problems need to be integrated with general health problems and extended in a basic manner to their families. It is interesting to note that in spite of their promiscuity, the emotional bonding of truckers still lies with their families. Openness within the family may change the entire scenario and messages on STDs/HIV/AIDS may reach their families. An integration with general health will eliminate the taboo attached to STDs and will open channels of communication within the families. We find that truckers have already started referring their wives to our intervention centres for treatment, but the proportion of such incidents is low compared to the gravity of the situation. (All estimates show that India will be the single largest reservoir of HIV-infected people by 2000 AD.)

Based on the emotional bonding of truckers with their families and their concern for their spouses and children, BPWT is now experimenting with a strategy called "Dialogue". This is a strategy to initiate and sustain communication on family health and STDs/HIV/AIDS within the families of truck drivers. We were involved in experimental stages of the strategy in two villages of Rajasthan, having concentrated on truckers. The objective was to initiate discussion on sex, STDs and AIDS between truckers and their spouses. We have identified some of the truckers' villages in West Bengal, Bihar, Orissa and Andhra Pradesh for replication of this strategy with the spouses of truck drivers.

BPWT has a long and rich experience in managing STD/HIV/AIDS intervention projects among the truckers. Although the focus of the projects is the trucking industry, this experience can also be applied to other vulnerable groups.

Reaching the Community through an Integrated Approach

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HALO Medical Foundation, Aurangabad (Maharashtra)

Introduction

As we enter the twenty-first century, health remains the primary necessity of the community. In the post-Independence era, the nation has experienced tremendous change in the fields of economy, industry, agriculture, education, as well as in the domain of health. The latest developments in medicine are known today in India, and many very major operations, comparable to those carried out in the West, are performed in our country. Unfortunately, on the other hand, the overall status of health in the country is not encouraging. Infant and maternal mortality rates, the incidence of communicable diseases, etc., still pose a challenge to our health services. The low socio-economic status of the society, ignorance, poverty, etc., are the main hurdles. The problem is worse in the countryside and that is why the rural area demands more attention than it receives today. However, the doctors, nurses and hospitals are unfortunately clustered in urban areas, while there is a dearth of health professionals in the rural areas. That is the reason why Mahatma Gandhi said many years ago "Go to the villages". In order to respond to the demand, in order to bridge this gap, an attempt was made in the form of the HALO Medical Foundation, established in 1992.

Background

The HALO Medical Foundation has its roots in a movement called HALO (Health and Auto-Learning Organization) which is run by medical students from the Government Medical College, Aurangabad; it was formed on 10 September 1980. As the Government of India was thinking to implement the ROME scheme (Reorientation of Medical Education) in medical colleges, the students voluntarily responded to the appeal made by Dr. Shashikant Ahankari and formed HALO. This organization is purely voluntary, non-political and non-religious. The organization is run entirely by medical students in their clinical term and intern doctors. The resident doctors and teachers also join whenever they find time. The main aim of the organization is to create health awareness in the society and social awareness among the medicos. The organization keeps in mind the fact that we ought to learn about the various social, medical, economic aspects of the disease from society.

Activities of the HALO movement

The activities of the organization are in the rural areas. One village in the vicinity of Aurangabad is selected each year. Initially, a village meeting is called in which the ideology of the organization is explained and the role of community participation is emphasized. Most of the preventive and curative services are rendered to that village during the year. Initially, a house-to-house health survey is conducted and an analysis is undertaken. Health problems are identified and tackled accordingly. Various activities include routine out-patients' treatment, an antenatal clinic, immunization, specialized multidagnostic camps, etc. A sanitation survey is also conducted and soaking pits are constructed wherever necessary. The organization has more than 150 exhibits prepared by the medical students in the local language and a series of exhibitions are held. Those patients who require specialized treatment are identified and referred to hospital. Along with the health activities, if possible and according to community participation, night schools, village libraries, *Mahila Mandals* are formed. Film shows presenting family planning and de-addiction are arranged. These activities are mostly incorporated in the existing government health system. Until now, HALO has worked in more than twenty villages with a population of 1.5 lakhs in the last seventeen years.

The organization also has many urban activities. In 1986, an inter-collegiate blood donation competition was started which may be unique in the state. Approximately 20-25 per cent voluntary blood donations have been collected through this competition every year at the Government Medical College Hospital, Aurangabad.

The poster exhibitions, especially those concerning communicable diseases, are arranged in slums and areas prone to epidemics. This activity played an important role in the polio epidemic in 1983. Simple, lucid language, pictorial illustration, informative content are some of the salient features of the exhibition.

The organization has also come up with a unique idea of "Health Education Camps" for college-going students of other faculties, such as Arts, Commerce, Science, etc. A three-day non-residential camp is arranged at the medical college in which basic health education is given. The organization has also published a book entitled *Shan Vaidyak*, consisting of primary health information.

The organization is about to complete its eighteenth year. During this time, it has seen a lot of ups and downs. The relevance of such a movement has often been questioned. Without any financial support, without any incentives, purely on a voluntary basis, the movement is still going on. This is a positive achievement. In the present days of economic liberalization, privatization and highly commercialized attitudes, the movement has rather more relevance and necessity.

The members of HALO, after graduation, felt the need of forming a trust which can serve society more effectively. Thus, the HALO Medical Foundation was established in 1992.

Philosophy of the HALO Medical Foundation

Fifty years after Independence, a majority of the population has no access to affordable health services. Eighty-five per cent of the rural population have to depend on the private sector for curative and allied services. A majority of these people even have no access to the presently existing health services. This is evident from the fact that only 39 per cent of the sub-centres and 73 per cent of primary health centres (PHCs) are functional. Many of PHCs do not have adequate drug stocks and the work of the staff is target oriented. India is a signatory of the Alma Ata declaration of "Health for all by 2000 AD". With the existing situation, the task is difficult. This goal is only possible when the health services reach to the grass roots and to the common people in the rural areas. Taking into consideration the fact that most of the modern health care facilities are located in the urban areas, while 80 per cent of the population is in rural areas, the Srivastava Committee, in 1975, proposed the concept of Community Health Volunteers (CHVs) (or village Health Guides). This proposal was accepted by the Government of India and became operative in October 1977. The CHVs were trained at PHCs and were responsible for carrying out preventive and promotive health services, for educating the people and giving first aid services. Nearly 70 to 80 per cent of the illnesses at the village level were controlled by these CHVs. But as time passed, the CHVs were neglected. Their importance was not identified. Because of the meagre remuneration, the CHVs also lost enthusiasm. Leaving aside the question as to who is responsible for this sorry state of CHVs, the damage has already been done. The HALO Medical Foundation strongly feels that if this CHV programme were to be strengthened in the right direction, goals could then be achieved.

The foundation also demands a demystification of medical knowledge on a larger scale. With the media explosion today and in the era of consumers' rights, mass health education should be carried out. People should be aware of the diseases they contract and the possible hazards. The best example of this could be AIDS. Lack of sex education is one of the responsible factors for the increasing incidence of AIDS.

The foundation is also concerned about the fact that public health occupies a low priority on the political agenda; the percentage of the total budget of the state allocated for public health has declined from 3.39 per cent in 1986-87 to 2.78 per cent in 1992-93. And, out of this amount, 60 per cent of the funds are spent on FP salaries and establishment costs. Though the foundation is non-political, we feel that the generation of a positive political will is very much necessary to bring about a change in today's health scenario.

We have a long tradition of herbal medicine in the form of *Ayurveda*. Herbal medicine is often locally available and useful. An integrated treatment should be developed, so that the best medicine with minimum side-effects can be given to patients.

All the developmental processes of the foundation are centred around women. Empowering women has been a mainstay of various programmes. It is believed and experienced that educating women is like educating the whole family. Being under-privileged for so long, they demand more attention.

Activities of the HALO Medical Foundation

The activities of the HALO Medical Foundation were started in 1993 after the unfortunate natural disaster of an earthquake in Latur and Osmanabad districts of Maharashtra State. Immediately after the earthquake, everyone rushed to the place to help in one form or another. The government and many NGOs left no stone unturned to execute the relief work and bring the life of the affected people back to normal. Health, housing, agriculture, education, rehabilitation and almost every area of relief work was carried out. But as time passed, the activity of the people diminished. Questions of permanent housing, rehabilitation, orphans, physically and mentally disabled, primary health care, etc., remained unsolved. It is necessary to have a long term programme in every aspect of the rehabilitation process. According to a survey conducted by the Tata Institute of Social Science, more than 8000 people were killed and more than 7000 people were permanently disabled. Identifying the need of the hour, the HALO Medical Foundation started the Bharatvaidya training programme in Latur and Osmanabad Districts.

Bharatvaidya Training Programme

The programme revolves around the basic faith that nearly 70 to 80 per cent of the prevailing diseases can be treated and prevented at the village level. A village-level health worker, "Bharatvaidya", if adequately trained, can take care of health needs very efficiently. The foundation launched its programme in the earthquake affected areas. A syllabus was prepared for training which consisted of twenty-one days of initial training followed by a seven-day refresher course. Training is conducted at the centre in Andoor built by the foundation. Until now, the foundation has trained eighty-five health workers belonging to eighty villages. At the end of training, the worker is provided with a medicine kit. The duties of the worker can be summarized as follows :

1. conducting a health survey of the village ;
2. treating minor and medium illness ;
3. registering births and deaths ;
4. antenatal care, registration, examination and immunization ;
5. daily house visits, health education, sex education for the AIDS awareness campaign ;
6. identifying high-risk cases and timely referral ;
7. performing deliveries ;
8. working for better environmental sanitation ;
9. organizing *Mahila Mandal_s* and forming self-help groups ;
10. co-ordinating with state health services.

The medicines are purchased from low-cost Gujarat. The worker is supposed to charge the patient as per the rate-card provided to her. This is an attempt to make the workers self-reliant. It is very interesting to learn about the work done by these workers,

The Bharatvaidya workers maintain a regular diary as part of their duty. The socio-economic and cultural dimension in their individual lives has undergone drastic change. Ultimately, the aim is the empowerment of women and the raising of their status in society.

Aarogyayatra

Immediately after the earthquake, the habitat of the villagers was changed. They had to leave their old houses and settle in an open field where facilities for sanitation, drainage, bathrooms and latrines were not available. There was apprehension regarding various communicable diseases and skin diseases in the rainy season. To create an awareness of the forthcoming diseases the *Aarogyayatra* (Health Tour) was arranged from 4 June

1994 to 14 June 1994. The *yatra* was organized in twenty villages. Thirty medical students stayed in Lohara for ten days and conducted this *yatra*. Two villages were covered daily. Handbills, a poster exhibition, slide and film shows were arranged. Kalapathak arranged street plays on various health issues. The impact of the *yatra* was very positive.

Suryayatra (Solar Fair)

The whole nation observed the phenomenon of the total solar eclipse on 24 October 1995. The People's Science Organization asking Pariwar, Ankoli, decided on this occasion to have a Solar Fair from 20 October 1995 to 30 November 1995. The main aim of the fair was to educate the community about natural happenings in the universe, as opposed to blind faith and superstitions. The opportunity was also taken to carry out mass-level science education. The HALO Medical Foundation was invited to assume responsibility for the medical part of the fair.

There were various stalls in the fair, such as a model of the universe, the conversion of solar energy into the thermal power, etc. The HALO Medical Foundation's Bharatvaidya training centre had one stall. Four Bharatvaidya workers conducted the stall each week and in all twenty-four workers were involved in this fair. There were eighty poster exhibits, a set of 100 slides and two video cassettes on communicable diseases. Along with this, patients with minor illnesses were treated by the Bharatvaidya workers. This was a very good opportunity and exposure for the health workers. The fair and stall were attended by more than 20 000 persons and college students.

Kalapathak

The HALO Medical Foundation has devised its own Kalapathak with all the necessary instruments. The street plays are conducted on various subjects like communicable diseases, leprosy, tuberculosis, etc. The main aim is to educate the community through entertainment and make them aware of various superstitions. The field supervisor and social workers themselves work as artists in the Kalapathak. The Kalapathak has received an overwhelming response in the community.

Exposure Tour

An exposure tour was arranged for the health workers to the various health projects. The aim was to bring about a reorientation in knowledge and to learn new things from the other projects. A tour was recently conducted which visited Masum, Pune, Ralegan, Siddhi (Annasahab Hazare) Vachan, Nashik, Bharatvaidyak Sanstha Dindori. It was an excellent mutual exchange programme and, surprisingly, it was the first time that many of the health workers had remained away from their villages.

Specialized camps (high-risk approach to primary health care)

It is a proved fact that in most patients cancer is detected in the late stages. The causes are multidimensional. Cancer pertaining to gynaecological disorders is detected late because the women get a low priority as far as their problems are concerned. Moreover, the problem is even worse when they are not sufficiently educated to examine themselves. The foundation, instead of calling the people or referring them to the higher centres, decided to organize the cancer detection camp in their respective villages. Intensive efforts were taken to educate the women to get themselves examined by the concerned specialist. Most of the women in rural areas hesitate to undergo internal examination. But, surprisingly, many of the women were examined. Routine gynaecological internal examinations were conducted. Papsmear, the test for the early detection of cervix cancer, was undertaken.

Self-help groups for women

The empowerment of women has been a key in the total development of villages. The foundation also wishes to take a keen interest in this subject. Bharatvaidya health workers have taken the initiative and formed twenty-five self-help groups so far. Through these groups, day-to-day family credit problems have been solved and new income generation activities have been started.

Integration of HIV/AIDS prevention

The earthquake affected areas are peculiar as regards human behaviour. On one hand, there is a great vacuum in the minds of earthquake affected people. And, on the other hand, they are given ample aid in the form of cash or kind. This "neo-rich" group has developed a behaviour, sexual and otherwise, which makes them vulnerable to the deadly disease AIDS. The frustration due to the consequences of the earthquake has resulted in some of them looking for easy solutions, such as alcoholism and drug addiction.

With all these things in mind, HMF started an AIDS awareness campaign in January 1997 in forty villages. The project was named "*Jivan Rakshan Prakash*". This project is funded by the Government of Maharashtra. The objective is to change the attitude and behaviour of people regarding sex and sex-linked problems, to control the spread of AIDS and to re-orient adolescents and youths towards becoming responsible citizens through education. For the effective implementation of this programme, a steering committee was formed under the presidency of a notable Gandhian leader and Freedom Fighter. The committee includes various government officers, deputy town officers, social workers, members of *zilla parishad*, *panchayat samithi*.

The staff recruited for this project was already working with HMF in various other health projects. There were five social workers (four males, one female), two ANMs, four field supervisors and a project co-ordinator. These twelve staff members were given seven days training in AIDS and sex education. Then the training for HMF Bharatvaidya workers was arranged in two sessions with an interval of thirteen weeks. After initial training, they were instructed to hold women's meetings, and after the experiences of two or three such meetings, they were called on for the next training. This method helped greatly in achieving the proper orientation of the training.

The resource persons invited for training were already working in AIDS awareness and counselling, and had undergone training themselves. In training, two-way communications, games, songs and group discussions were used, along with OHP slides and video cassettes.

After the training, these women started conducting *Mahila Mandal* meetings and are giving AIDS and sex education to the other village women. Along with the members of the *Mahila Mandal*, their daughters also attend the meetings. The average attendance per meeting is about eight to twenty members. In the last ten months, 650 meetings were conducted and about 9 000 women and girls have been trained in the subject of AIDS in forty villages. The social workers and field supervisors attend about 50 per cent of the meetings arranged by Bharatvaidya and help them in solving technical problems.

Initially, there was a reluctance on the part of the women to talk about sex education, but unfortunately seven to eight patients in the project area died due to AIDS. After that they were eager to know more details about this new disease.

The facts coming out of these inter-women discussions are as follows :

They discuss frankly with each other in the absence of males. They are ready to receive knowledge from Bharatvaidya workers (females). Most of the village women do not know about condoms; many of them have not seen one. Many housewives know about the character of their husbands, but are unable to control them.

As per the suggestion of the steering committee, village-level AIDS awareness committees have been formed in all project villages which included *sarpanch*, leaders of *Mahila Mandals* and youth club teachers and a few respected persons.

In the months of April and May 1997, the training programmes for committee members were arranged in fifteen villages and about 1600 youths (male and female) were trained in these camps.

HMF "*Sawadhan Kalapathak*" presents programmes with songs, *bharuda_s*, *bhajan_s* and drama in the local language. In addition to AIDS awareness, the *Kalapathak* also educates the people to overcome superstition, illiteracy, etc. The *Kalapathak* programmes were arranged in sixteen villages which were attended by about 180 people in each village. It is found that *Kalapathak* is the best media for mass-level health education.

The district superintendent of police of Osmanabad arranged an AIDS awareness camp for police and truck drivers on 5 May 1997 at Osmanabad. The HMF was invited as a resource agency for training, and we have trained 800 policemen and truck drivers concerning AIDS.

Since 1990, once a year HALO has been organizing health education on AIDS awareness to adolescent school girls in Aurangabad. During all these training sessions, pre- and post-tests were conducted and a remarkable improvement in knowledge was observed.

Seva Mandir : an integrated approach to the AIDS outreach protection programme in Rajasthan

Veer Pal Singh & Dashora, G.K. Seva Mandir, Udaipur (Rajasthan)

Every day, about 8 000 trucks ply up and down National Highway n°8 between Delhi and Bombay. At various points along the way, rustic tea stalls known as *dhabba_s* (restaurants where people can rest on a bed) line the roadside. Day and night, weary truckers pull up for tea, food and a chat, and also to purchase sexual favours from local women. This highway, like others throughout the country, is thus a major route not only for goods, but also for the spread of STDs, including HIV.

The truck stop near Udaipur, in southern Rajasthan, is extremely popular with truckers. But the *dhabba_s* here now display colourful stickers on safer sex, and have eye-catching condom dispensers with a ready supply of free condoms. The *dhabba_s* workers also hand out pamphlets on AIDS to the truckers, and chat with them about protecting themselves against STDs and AIDS.

A Vulnerable Population

The AIDS prevention activities at the *dhabba_s* near Udaipur were started by a local NGO, Seva Mandir, meaning “ Temple of Service ” : the name reflects the Gandhian ideals which underlie the organisation’s approach to development. For the past 25 years, Seva Mandir has been working with the local tribal people, the Bhils, in a wide variety of rural development programmes.

There are not yet many known cases of HIV infection or AIDS in the area, but social, economic and geographical factors combine to make the local population vulnerable to STDs, including HIV. Much of the region has been ravaged by deforestation, environmental degradation and drought. With little or no income from the fields, many of the area’s men have left their families behind and gone to big cities such as Ahmedabad in search of work. In the cities, they are increasingly likely to contract HIV and then bring the virus back to their families and communities.

Near the highway, tribal women resort to selling sex to the truckers in order to survive, placing themselves at risk of contracting HIV, and then passing the virus to their husbands and other sexual partners. Most these women are not full-time prostitutes, but sell sex whenever in need of cash. *Dhabba-s* workers or other brothels usually make the arrangements with the women’s clients. In addition, premarital and extramarital sex is common and widely accepted among the Bhils themselves.

“ STDs are common and condoms are not yet widely used, so HIV infection is bound to be present and spreading ” says Aja Mehta, Seva Mandir’s Programme Director. We proceed on that assumption, and we don’t think that verifying the presence of HIV is a priority.

For Seva Mandir, however, HIV/AIDS is not just a health issue, but a social malady linked to the endemic development problems of the area. We are trying to address both the question of chronic poverty and the lack of health awareness, in the hope that the spread of HIV can be slowed down before it assumes epidemic proportions in this area, says Ajay Mehta.

Contact teams

Seva Mandir’s AIDS programme began in April 1992, with a conference in Udaipur aimed at giving 400 governmental and non-governmental grassroots workers a basic understanding of HIV and AIDS. To gain public support for the programme, the staff organized rallies in Udaipur and the villages where they worked, holding aloft banners with AIDS messages. Films were shown using an audio-visual van to attract crowds of people, who were then given pamphlets on HIV and AIDS.

The following month, Seva Mandir allotted new responsibilities to its different cadres of village-based health and development workers, most of whom are part-time volunteers, although some receive a monthly stipend for working on a full-time basis. The cadres normally work on a variety of projects, including health, adult literacy, and water conservation through the construction of *anicut_s* (mini-dams) across the rivers and streams.

First, six highway contact teams were formed to contact local women, *dhabba* workers and other sex brothels. Each team is headed by a community health worker who lives near the highway and enjoys a good rapport with the *dhabba* workers, brokers and sex workers. Four village-level health workers, were formed to visit communities living more than 25 kilometres from the highway.

The team members were trained to discuss the basic facts about HIV/AIDS and STDs, to distribute condoms, and to refer villagers to Seva Mandir's Health Officer for STD treatment. They were then assigned five villages each to visit on a regular basis. Team members travel from village to village, staying for two or three days in each, and discussing HIV/ AIDS and other health issues with village leaders and groups of families. They also distribute small supplies of condoms to those who request them. At night, the team performs a *bhajanmandali* (a kind of traditional folk theatre with music and songs) which they themselves have scripted, explaining how HIV spreads and what one needs to do to protect oneself. They often visit the local *dhabba* _s and talk to the workers about HIV/AIDS and other STDs.

Team members carry out these and other health or development activities for a few days every month, and resume farming at other times. They are therefore always available to their communities for help and guidance.

Integration

To bring an element of HIV/AIDS awareness into all its programmes, Seva Mandir has trained all its staff and volunteers in the basic facts about the HIV epidemic. Among the first to be trained were family planning workers and traditional birth attendants (TBAs), who now talk with people about protecting themselves by abstaining from sex before marriage and fidelity within marriage. They also promote condoms as having multiple advantages, ensuring contraception and preventing the spread of STDs and HIV, without side-effects.

We also train the TBAs to ensure aseptic conditions during delivery', says Assistant Health Officer Dr. Rupshri Bakshi. "They now take extra care to protect themselves when mopping up blood spills after delivery and disinfecting the area thoroughly.

"Many of the women in the village where Seva Mandir works suffer from STDs. We have to strengthen women's capacities and boost their confidence so that they can reduce their vulnerability to sexual exploitation, unwanted pregnancy, STDs and AIDS, Ò says Dr. Chandra Bhandan, co-ordinator of the women and children's development projects. As a first step towards encouraging women to discuss their problems and exchange experiences, local women have organized themselves into about 80 groups which meet regularly.

Young people are also being reached with information about HIV and AIDS through Seva Mandir's school health education programmes. Health educators discuss problems related to puberty, personal hygiene and sexual responsibility with other students. A workshop for adolescents from the villages, including those out of school, was used to educate boys and girls on sex, pregnancy, STDs and HIV/AIDS.

Seva Mandir also uses its water conservation and adult education projects to convey information about HIV and AIDS to the villages. We know that AIDS awareness could not work in isolation, says Ajay Mehta, so we have made it an important aspect of our economic development programmes. We explain in simple detail how falling ill with AIDS will reduce people's productivity in the field and so reduce their earnings.

Seva mandir's AIDS programme presently covers about 200 villages and is carried out by project staff as part of their normal duties. The formation of the highway contact teams and village contact teams has helped to sharpen the focus on HIV/AIDS and to ensure that condoms are available for the villagers whenever needed.

Problems and Solutions

The first difficulty in starting the programme was in convincing Seva mandir's own staff that HIV and AIDS would soon create major problems in the communities where they were working. It was hardly surprising that this was difficult, since no one from Seva Mandir had ever seen anyone with HIV or AIDS.

It took a great deal of motivating on our part to convince them that they owed it to their communities to act before it was too late, says Seva mandir's Health Officer, Dr. Lodha.

Seva Mandir therefore included HIV/AIDS education in its STD prevention, family planning and reproductive health programmes. The workers involved in these programmes had seen and were familiar with STDs, and understood that the same behaviours were responsible for spreading HIV. Workshops were held to help workers open up to the prospect of having to talk about sex in very explicit terms.

The programme also faced external difficulties. Women selling sex and their brokers, who felt that Seva mandir's AIDS programme threatened their livelihood, were initially hostile. With skilful handling, however, an uneasy truce has been reached. There was no difficulty, however, with the *dhabba* owners and their employees, who were soon convinced of the important role they could play in preventing the spread of HIV and other STDs.

Every three or four months, Seva mandir's community health workers take out questionnaires to the villages where they work and complete them, based on discussions with village people. This helps Seva Mandir evaluate the efficacy of its HIV/AIDS programme. So far, the responses are generally encouraging.

People now know about AIDS and understand the dangers of high-risk behaviour, says Dr. Lodha. Group discussions with the villages and *dhabba* workers are showing that condoms are being increasingly demanded and used. There were initially problems with the disposal of condoms after use, but villagers are learning to discard used condoms into pits.

Seva mandir's AIDS programme is not separately funded, but utilizes small amounts from the money allocated for its other projects. Plans are underway to extend the programme to all 500 villages covered by Seva mandir's development projects. It is expected that about 1 000 part-time workers, all of whom reside in the villages, as well as 200 full-time workers, will be involved in the programme.

Through its AIDS programme, Seva Mandir has used its long-standing relationship of mutual trust with the communities where it works to promote more responsible sexual attitudes and safer sexual behaviour. The programme is integrated with the organisation's development projects, which have helped rural communities to achieve a measure of economic and social progress. The staff and village-based volunteers carrying out the HIV/AIDS awareness programme are the same as those involved in Seva mandir's other health and development activities. The changing social environment brought about through the programme is helping to give individuals and communities the option of breaking away from high-risk sexual behaviour, and to choose instead forms of sexual expression which greatly reduce their chances of becoming infected with HIV.

Case Studies

Lalitha

Lalitha is a community health worker who heads a village contact team in Seva mandir's AIDS programme.

"Now that we know of AIDS, we help our people to understand how it can affect us all. We explain that there is more than one way to avoid getting the disease, like avoiding sex altogether, being true to one's husband or wife, or always using condoms the right way".

We distribute condoms directly to people in our village. We have always spoken of condoms as a family planning device and we now explain that they can also protect people from STDs and AIDS. The unmarried men in our villages sometimes hesitate to take condoms from us. We know men keep taking the condoms from the dispensers kept in the *dabbha*s.

Many women sell sex to truckers without the knowledge of their parents or husbands. Women come to me frequently with complaints of vaginal discharge. Many of these turn out to be STDs. The men also complain about these problems to the village-level health workers.

Most of the women here are married very young, before the age of 15. They often come to me for advice on how to avoid pregnancy and how their husbands should use condoms. They discuss their family problems with us as well, and many complain that their husbands visit sex workers. I try to explain that their husbands should not do such a thing as they might contract an STD or AIDS. Here, when a husband cheats on his wife, the wife can and does talk to him and if he still does not listen, the women get together to try and convince him not to.

Kanniram

Kanniram is a married man of 30 with two children. For the past 15 years, he has been running a *dhabba* off National Highway n°8 in Rajasthan. He first heard about AIDS from Seva mandir's health workers. Today, his *dhabba* displays posters and stickers on AIDS and he hands out pamphlets to customers.

With thousands of trucks from different parts of the country passing by, the *dhabba* does brisk business. The AIDS posters and the condom dispenser invariably spark off a discussion on AIDS amongst the truckers. Kanniram and his workers explain how condoms can give protection against AIDS and more immediate problems like STDs. There is now a great deal of awareness among the truckers and most do not leave the *dhabba* without stocking up on condoms from the dispenser installed and supplied by Seva Mandir.

Nearly 50 women in the area sell sex, serving both the truckers as well as a considerable number of men from Kanniram's own village. STDs are widespread, but the village men have begun stopping at the *dhabba* to pick up condoms before visiting the sex workers. However, the problems of STDs remain as some times the condoms tear during sex. When this happens, the men wash themselves with water and urine, in the mistaken belief that this will cure them of any STDs they might have contracted. They are sure that the practice will also protect them from AIDS.

In addition to visiting sex workers, some of the truckers have sex with one another. Kanniram worries that this may be very dangerous as they do not use condoms at these times. He himself is in love with a married woman in the village. They do not use condoms, but he believes she cannot give him AIDS as she seems to be faithful to her husband-and to Kanniram. The woman's husband is an agricultural labourer who, as far as Kanniram knows, does not visit sex workers.

Discussion

K. Santosh : How did you come to be own involved ?

V. Singh : I started Seva Mandir and have been working for the past twenty-five years with the local tribal people who are living in a small village situated on the National Highway n°8 between Nellai and Bombay. At various points along the way, a number of tea stalls have been installed for the truck drivers who stop their trucks for taking food or tea. Near this highway, many tribal women are involved in prostitution with truck drivers and are passing the virus to their husbands and other sexual partners. Most of these women are not full-time prostitutes. But they sell sex when they are in need of money. Many pimps are working in this area. Seva Mandir has been working for these people and has conducted many awareness programmes.

General Discussion

Prof. Shanmuganandan : I will take this opportunity to indicate several points which were raised during this seminar. We have discussed diverse issues related to HIV/AIDS, as well as the involvement of NGOs in prevention activities. The different sessions included many papers discussing the various aspects of HIV prevention. I would like to mention some points on the basis of what we have discussed so far, and I would like to have responses from the NGOs, members of institutions, research scholars and administrators who are present here. We initially talked about the networking of NGOs in order to discover more precisely the various areas in which they have been working, and in order to share their experiences. Moreover, to keep the data base which can be supplemented by NGOs, it is very useful to inspect the resolutions. I would like to know, particularly in this context, whether we need an organization and networking of NGOs at the national and state levels. I would like NGOs to say something about this. As NGOs, we face a lot of problems working in various areas. We also have difficulties with the administration and other institutional bodies. This point has been raised to learn exactly what the opinions of the NGOs are so that their representations can be referred to higher authorities to fight for the rights of those living with AIDS and to lobby for the best we can offer in terms of support and an adequate social environment for the infected people. This will be important for the prevailing discussion in India. In addition, we must draw up guidelines for the NGOs. NGOs can come forward on national, state or district levels so that a network can be established to find out who is doing what. On the one hand, NGOs are contributing to research, helping the planners to know in which direction their policies should be oriented. On the other hand, planners can improve the situation as well as NGOs. They can also expect to receive from NGOs knowledge and trends regarding the HIV infection among the targeted population. This form of complementarity is found throughout the world. And such a seminar as this gives ideas to the NGOs as well as to various people concerned in the struggle against the epidemic. Some NGOs have presented during these three days very good and valid points regarding particular aspects of the problems we face, of which women's empowerment is the most important aspect. I hope the National Commission on Women, along with other representatives of various women's organizations, can take up this particular necessity of empowerment. Women must no longer be considered as second-rate citizens and they should no longer be held in subordination. This is important also because women play a major role in decision-making for the economic development of the country. This is something I have experienced, as well as a suggestion. People living with AIDS will be given a fully supportive environment, and we must allow the NGOs to look into matters and to provide all possible support, even at the levels of the government and funding agencies, for it is becoming a grave problem. Indeed, NGOs are in a way all doing good work, whether we call it research or field work. The knowledge we gained in the workshop is very significant. NGOs should take part in all activities of the government's planning process. Some NGOs are enlisted in the Tamil Nadu State AIDS Control Society. But this apex body must keep in touch with all NGOs to represent their views to the government.

Dr. P.K.Das : Technologies are sufficient to control many diseases. But in the implementation process we have very often failed. For example, Europe and all other developed countries have controlled many of the diseases without any sophisticated technologies or vaccines or drugs. While we are working we should be aware of stigmatizing. There have been discussions about NGOs, their roles and limitations. We are all working for the same purpose and I don't find any reason for conflict. NGOs have different dimensions but are all working for the mitigation of the epidemic. In some fields NGOs are good; in some fields the government is good; in some fields the community organization is good. Awareness should be extended to a larger scale, rather than concentrating only on commercial sex workers. Focusing on a modification of the Immoral Traffic Act is no doubt necessary, but the subjective dimension of morality and immorality should be kept apart. Another point very commonly observed is that the NGOs have been conducting awareness campaigns and have been calling the commercial sexual workers to meet at certain places. Interpersonal communication must not be so exposed. I would request all the NGOs working with commercial sex workers to be very secretive, rather than calling on them. Probably, some of the health workers can go there and do the work. It may be difficult, but they should try, rather than calling them to meet at a particular place, which could create unnecessary impressions. For example, if a policeman calls on you for some purpose, society may think that you are a criminal. If a woman working for the prevention of AIDS comes out of the STD clinics or from the office of an NGO, the public may think that she is a main cause of AIDS. We have spoken so much about AIDS, but what are we doing for STD prevention at a time when a treatment is available? We have to examine whether the STD facilities have been properly used and if the way of approach is correctly followed without any negligence or discrimination. Because STD-affected people are very sensitive. But so many unnecessary questions, which are supposed to be part of the investigation, are asked of the infected persons. How many people have you attended? How much money did you get from them? No, this is not our business. Ethically, we cannot ask them such direct questions. People are really sensitive and, in a repressed society like ours, they feel very bad when being forced to answer such questions (for the sake of the statistics in government hospitals, for instance). Doctors sometimes do not realize the extent of the harm they cause their patients. This is one of the major problems and with HIV/AIDS we have to be even more careful.

Viswa Deepak : I am a research scholar, a pure academician. During the whole conference, I found that almost all delegates have spoken about behavioural change to prevent HIV/AIDS. In this regard, I have myself asked whether it is possible to change an individual's behaviour, especially through counselling. If not, what should be our approach to make behavioural change sustainable, other than counselling and condom promotion? What should be the alternative approaches?

F. Bourdier : Is there any NGO who wants to answer this question? In fact, we have just touched the surface of the problems. During these three days, only few of us have noted the main social forces which are liable to prevent any behavioural change in a particular context. I am not as enthusiastic as Prof. Shanmuganandan because I do know to which extent we have been able to establish a real communication amongst ourselves. We have spoken of counselling, empowerment, research, sexual behaviour and of many other “ key ” issues, but I have the impression that we give a different meaning to these concepts according to our backgrounds.

David Thiagarajan : We have found that the involvement of the community is the major factor towards improvement. It is an outcome indicator of sustainability and it has to be realized at the community level. The second point is the funding of the organizations. If we are in conflict with the policy of the funding organization, we will have problems. We are able to bridge the gap between the funding agency, the policy-planner and other NGOs. So, we have to work at the grass roots level to mobilize the community and to impress upon the policy planners, to impress upon the funding instances, the needs of the community. NGOs are the vital link between the community and the policy-planners. But to convince the planners, we need to gather our data because any government needs information based on a representative scale.

Viswa Deepak : How many NGOs are working like you? To provide a good example, NGOs fought against ODA (Organization of Development Aid from the United Kingdom) in Kerala. They fought against the arbitrariness in the *a priori* designation of groups as high-risk.

Dr. S. Shukla : One cannot change this in a single day. It may be possible through NGOs, but NGOs cannot become responsible for the whole development process. They are just a part of it. But the government or the funding agencies are expecting much from NGOs in India, and the latter are not giving enough feed-back, whereas they could act more intensively as a helping hand to government bodies. In many countries, a proper government orientation is given by NGOs and awareness automatically reaches the targeted people, who in turn become responsible for changes in people's attitudes. So the government, NGOs and every individual in the targeted population are responsible for the behavioural change in a community or society.

S. Surender : Now a committee in Mumbai is trying to bring out a code of ethics, with social workers and NGOs. So in one or two years we will be ready for an agreement between funding agencies and NGO organizations in which we can change our terms or not.

Ramkumar : As far as behavioural change is concerned, we are working and planning according to training imported by the funding agencies which includes some strategies from research. Research scholars should find out whether this training is adequate or not.

F. Bourdier : Mr. Ramkumar, you are involved in implementation and you deplore that some “ external forces ” are compelling your organization to focus on a given aspect. I feel that you have confined yourself too much and that you should have the courage to either reformulate the guidelines imposed on you, or to refuse a project if you find it irrelevant.

Man respondent : All NGOs ask the government to keep their own identity to work. Money also encourages the development of NGOs and this is something we cannot deny. Without a minimum of money it is impossible to achieve anything. When NGOs face difficulties, some problems can be solved by money. For example, I carried out an AIDS control programme. I had nothing from the government. But I wrote to five medical companies in Africa which are currently spending many millions of dollars for control programmes throughout the world. They gave us all drugs free. Where there is a will, there is a way.

T. Sethulakshmi : I would like to make a specific point about disseminating information. In rural areas, there are often no facilities for slide programmes. In place of slides, one can make use of a "view master", which is rather like binoculars. It can be used for condom promotion and to show how to use condoms. A person can, without shyness, view the view master slides. We are a ten-year old NGO. We have experience and can manufacture on a large scale and supply everything according to different situations. It is a marketing strategy mixed with communication skills. That is the first point. The second point is about marriage between HIV-positive people. This has already been done in Bombay by Dr. I.S. Kilada, J.J. Hospital, Mumbai. He has organized weddings between HIV-positive people. This can also be taken up by NGOs and others.

F. Bourdier : I follow you, but regarding marriage between HIV- positive persons, the question arises as to how an outside person can be in a position to organize such an arrangement?

T. Sethulakshmi : In France, you do not have this custom, but in our country arranged marriages are the norm. In India, it is also common to see collective marriages where one or two hundred people get married at the same venue. Such weddings have been conducted by the government in Tamil Nadu, mostly to assume the marriage costs for people from lower socio-economic strata.

S. Shekar : We have conducted some marriages. And Dr. Manorama knows that we jointly conducted a marriage for a couple based on their own decision. We cannot influence them to get married to each other. They had received counselling and had been interacting before any decision was taken. We are cautious that it should not be a parental decision. There is no need for publicity.

Man respondent : Some of us are not being realistic. We must start at a very low level. Many social workers do not know what HIV/AIDS is or how the virus is transmitted. They should at least have a basic knowledge. I request all NGOs to teach their workers the basic medical facts.

F. Bourdier : This is not solely the responsibility of NGOs, but is strictly everybody's responsibility. Those who are willing to be involved in the field must proceed because at present, in 1997, clear information is available in India. Of course, that does not prevent NGOs from encompassing this work. But NGOs should not become a pretence for demobilization and passivity.

Usha Raghavan : With the help of the Tamil Nadu State AIDS Control Society, we have educated all the government officers, and staff members at the State AIDS Control Society in Chennai working in the field of AIDS were given training. But one deplores the limitation of their knowledge, inasmuch as the one-day training session is far from sufficient. This is not the case for NGOs who have been trained in the field.

Marry Finch : During these three days, NGOs have been severely criticized. I have the feeling that those present at this workshop will lose confidence after having been attacked on different sides. One has to realize that we, the NGOs, are venturing in a very complex matter and whatever we try, we believe in it, even if we later realize our mistakes and change our strategies.

F. Bourdier : This workshop gives us a picture of the problems in the field of HIV. As Marry Finch said, it is easier to criticize in terms of negative drawbacks than to undertake a constructive action. But research work can be criticized in the same way. It is not the intention of anybody here to point specifically at the NGOs. Perhaps research can help NGOs to highlight certain facts. Similarly, research is an attempted deconstruction prior to any reconstruction. Most of the time we offer criticism, but we do not feel well about undertaking a prospective work. Even if we do this, it is generally easier to propose and think about something than to successfully implement a project. This is a fact we cannot deny. I am a researcher. I do not act, I do not implement. I just try to observe and understand. Even if sometimes I have to be involved, I am not confronted directly with many of the external problems that people are facing in their lives. In that respect no researcher can blame NGOs and use the criticism of them as a leitmotiv.

Ramkumar : We take your criticism in a positive manner. Actually, this workshop has been very informative, educational and therapeutical. I am adding the last word specifically because different-minded people from all parts of India have met here together.

Dr. P.K. Das : I really appreciate your concern about the criticism that has been meted out. Basically, I am a very critical person. Whenever I have a scientific advisor who does not criticize me at committee meetings, I generally remove him from the advisory board. Because, criticism is the best way to cleanse oneself. There is a proverb in Hindi to the effect that, if I hurt anybody's sentiment, I personally apologize; but that does not mean it was intentional and to the purpose of raising counter-issues. In my work, if somebody criticizes me, I feel happy. If somebody says that I have done something wrong, I will say, yes - because it means that I am doing the job. The man who does not do anything does not make any mistake. So you should not take criticism in its negative dimension and understand it as finding fault with you. Criticism is just to increase your credibility and has been done with very good intentions. For example, you have the capabilities and have undertaken a lot of research. But its real value will not be acknowledged because of the method which has been used. The credibility is very low. So to make you more credible we criticise you regarding methodology. You should take that as a positive message: you are doing your job. Some persons have said that we are expecting too fast a change, and that such a change cannot come to pass in a single year. Someone may provide a correct answer, but there may be something wrong with the expectation of the other. I was probably expecting too much. We certainly do not want to hurt you, but we would like to participate modestly in the improvement of the quality of your work. I compliment all of you for the work you are doing in spite of the tremendous difficulties.

Conclusion

Frédéric Bourdier et K. Santosh

Ce séminaire national organisé à Pondichéry en novembre 1997 avait pour double objectif de brosser un tableau succinct des ONG indiennes impliquées dans le domaine de la prévention sociale et individuelle du sida, et de voir quels étaient les liens théoriques et pratiques entre spécialistes des sciences sociales et acteurs du développement.

On se propose de tracer, en guise de conclusion, un bilan provisoire à partir de questions qui gravitent autour de ces deux thèmes. Pour comprendre l'ambiguïté des relations entre recherche et action dans le sous-continent indien on envisagera les enjeux de la politique nationale vis à vis de l'épidémie en mettant l'accent sur le rôle et la place dévolue aux ONG et aux chercheurs en sciences sociales, puisque notre hypothèse de départ vise à un rapprochement des deux. Compte tenu de ce cadre général on examinera les conditions d'application effectives de la recherche dans le domaine qui nous concerne. Enfin, on se penchera sur les lieux et circonstances de rencontre qui conditionnent les liens entre chercheurs, décideurs et agents du développement, pour nous interroger *in fine* sur le sens et la finalité d'un séminaire comme le nôtre.

Ce qui est évoqué dans cette fin d'ouvrage découle essentiellement des présentations et des discussions qui se déroulèrent à Pondichéry. Il nous est apparu cependant nécessaire d'actualiser certains faits à partir d'informations obtenues depuis, tout en s'appuyant sur les récents développements de la recherche et des stratégies de prévention en Inde.

Entre politique et recherche

Bon nombre de personnes d'horizons divers ont le sentiment d'avoir leur mot à dire et entendent participer, d'une manière ou d'une autre, à la lutte contre le sida. D'une manière volontairement tronquée et schématique, on peut distinguer ceux qui se consacrent à la compréhension et à l'observation des faits, et ceux dont l'objectif est de modifier les comportements humains, de planifier les programmes d'action. Il va sans dire que les relations entre ces acteurs vont de la méfiance à la collaboration en passant par la cohabitation, et que l'idéal de complémentarité est rarement atteint.

Les politiques (politics) en matière de prévention

La politique indienne dans le domaine de la prévention du sida ne peut se comprendre sans considérer les dynamiques externes et dynamiques et internes qui la gouvernent. Face à une épidémie dont les agences internationales n'ont cessé de souligner la gravité dans le pays, les acteurs locaux construisent des discours en réaction à cette accusation d'une Inde qui, sans appui allogène pour contrecarrer le sida, irait à sa perte. Il arrive ainsi que les conditions d'intervention suggérées/imposées par les bailleurs de fonds soient remises en cause tant par les pouvoirs publics, les représentants d'organisations locales que par les populations elles-mêmes qui ne veulent plus d'une approche incompréhensive qui heurte leur dignité. Ce point, s'il ne fait pas l'objet d'un discours officiel, nous a été maintes fois évoqué en catimini par les différents protagonistes du développement. Discours ambivalent puisque l'aide arrive massivement de l'extérieur dans la mesure où depuis les années soixante-dix, l'Inde a toujours adopté la politique de l'OMS. Lors de l'apparition du sida, les lignes directrices des stratégies décidées par l'organisation genevoise furent appliquées, en dépit de certaines objections ayant trait à l'épineuse question (toujours en suspens en certains milieux) de la spécificité indienne (résistance naturelle et sociale de la population à l'épidémie). L'état du Tamil Nadu fut le seul à parvenir à mettre en place un organisme (TNSACS) capable de recevoir les fonds directement de l'étranger sans passer par le gouvernement central. En 1996, ce même état reçut pour la lutte contre le sida la somme conséquente de 40 crores de roupies (400 millions) pour les deux années à venir: environ 90% des fonds provenait de l'OMS via la Banque Mondiale alors que le reste émanait de NACO à Delhi. Raison de cet engouement: le Tamil Nadu avec ses 500 à 600 ONG (il n'y a pas de recensement exhaustif) est considéré comme un modèle de réussite en matière de prévention et d'awareness. Parallèlement, l'agence d'aide américaine (USAID) par le truchement d'APAC déverse des sommes considérables dans l'état du sud.

Ces agences internationales parlent de sustainability, ce qui signifie essentiellement renforcer les structures locales: celles du gouvernement pour TNSACS et celles du secteur privé pour USAID. Mais cette intégration est battue en brèche par la compétition, la lutte pour l'hégémonie, le

clientélisme et la corruption qui nuisent à tout effort de concertation commune en vue d'une stratégie globale cohérente. Qui plus est, les modalités d'intervention diffèrent en plusieurs points: TNSACS se consacre pour beaucoup à l'awareness through education tandis qu'USAID encourage les projets de prévention sociale et, récemment, de soins aux personnes atteintes. Par ailleurs, la plupart des ONG ayant pignon sur rue (YRG, DESH, SIAAP, etc.) drainent des fonds qui leur viennent directement d'autres sources extérieures. Ces ONG influentes, qui développent leurs propres réseaux intérieurs en ralliant des ONG plus modestes et dépourvues de financement, n'hésitent pas à s'opposer de front avec la politique nationale qu'elles jugent frileuse, statique et inactive.

Dans ce contexte, force est de reconnaître que la promotion de la recherche par les deux agences internationales citées plus haut est pauvre si l'on compare avec le nombre impressionnant de projets mis en place. Les rares recherches qui sont subventionnées sont limitées dans le temps (maximum trois mois) et appartiennent à un type très particulier d'investigation sociale: il s'agit essentiellement d'obtenir des données statistiques, des opinions générales et de réaliser des enquêtes KAPB. Ce qui est recherché ce sont des renseignements d'ordre pratique censés faire état de ce qui se passe en un lieu donné à un moment précis à l'image des base line surveys, des surveillance surveys. Citons par exemple une enquête destinée à savoir combien de routiers s'arrêtent sur tel tronçon de route, quels sont ceux qui mettent des préservatifs et qui sont au courant du risque qu'ils encourent à fréquenter les prostituées. Une tendance récente de la part de certains bailleurs de fonds comme la Communauté Européenne, la Banque Mondiale, ODA, est de promouvoir des recherches systématiquement assorties d'intervention, tandis que d'autres telles la Fondation Ford, la Fondation Rockefeller encouragent des recherches innovatrices sans exiger en contrepartie une intervention immédiate.

La place de la recherche en sciences sociales

Partons de deux observations paradoxales avec ce qui vient d'être dit: la recherche actuelle en Inde sur l'épidémiologie sociale du sida se développe à grande vitesse et s'oriente très nettement, voire de manière quasi exclusive, vers une mise en application. Elle se dirige vers l'application en raison d'une demande expresse, fort diversifiée mais qui n'est pas toujours ce sur quoi un chercheur aimerait se pencher. La nature même de cette demande est source de malentendu car il n'est pas toujours facile pour un responsable de projet d'action de cerner l'objet d'étude d'un chercheur en sciences sociales. Compter les routiers qui font une halte dans un *dharba* (restaurant de bord de route) du Rajasthan, recenser le nombre de préservatifs distribués est un travail technique qui n'exige pas l'intervention d'un spécialiste des sciences sociales. Par ailleurs, la manière dont sont formulées les questions que l'on pose à un chercheur correspond rarement à la manière dont ce dernier aimerait qu'elle soit posée. Malheureusement, au dire des chercheurs indiens, leur marge de négociation est minime en ce domaine et peu sont en mesure d'intervenir réellement sur le déroulement d'un programme de développement, exception faite de rares personnalités scientifiques membres de la planning commission ou de l'Indian Council of Social Science Research.

Rares sont les universités en Inde dont les départements de sociologie, économie, géographie ou anthropologie ne consacrent une partie de leurs activités de formation ou de recherche autour du thème du sida. Nombreuses sont les thèses en cours qui abordent les dynamiques spatiales et/ou sociales de l'épidémie, le niveau de connaissance de la population, ou bien un aspect socioculturel de la prévention. Cette mobilisation déborde largement le milieu universitaire et se retrouve dans les collèges d'enseignement supérieur et dans les nombreuses institutions à vocation professionnelle qui, à l'instar de la Madras School of Social Work, ont une longue tradition d'éducation et d'initiation à la recherche (travailleurs sociaux, relations dans l'entreprise). Au niveau national, la recherche sur le sida se retrouve encore dans les antichambres de l'Indian Council of Social Science Research et l'Indian Council of Medical Research qui constituent les deux organismes publics prestigieux de la recherche académique, l'un en sciences humaines et l'autre en médecine. Viennent ensuite se greffer des instituts nationaux créés depuis l'avènement du sida comme le National AIDS Research Institute (NARI) à Pune dans le Maharashtra, et des associations privées de recherche dont le nombre va croissant: certaines se présentent comme des agences de marketing social à l'image de la société AIMS Research (Asian Information Marketing and Social Research) établie dans tous les états de l'union indienne et qui a été le fer de lance d'importants projets de recherche sur les comportements sexuels et les facteurs de risque au regard à l'épidémie.

S'il est possible dans le milieu universitaire de trouver des personnes travaillant dans une perspective purement académique, force est de reconnaître que la majorité des chercheurs est encouragée (mais sans financement automatique) tant par les agences nationales qu'internationales à entreprendre des études préalables, et surtout pour réaliser des évaluations, estimer la faisabilité de programmes d'action, sans que cela signifie pour autant que leurs travaux soient pris en considération ultérieurement. Il n'est donc pas exagéré de parler d'engouement pour les travaux concernant la pandémie.

Aucune pathologie endémo-épidémique n'avait jusqu'alors mobilisé tant de ressources humaines et matérielles alors que l'hépatite virale, le paludisme, la tuberculose, les carences nutritionnelles et les maladies infantiles déciment davantage la population indienne.

Les applications de la recherche

Il ne s'agit pas ici de rentrer dans le débat, passionné, entre les protagonistes de la recherche appliquée et ses détracteurs mais de voir dans quelles circonstances, en quels lieux, et sous quelles conditions la recherche en sciences sociales, notamment l'approche socio-anthropologique, participe à la compréhension de phénomènes censés éclairer les responsables de la lutte contre le sida.

Quelques principes fondamentaux

Toute recherche institutionnelle publique ou privée s'inscrit dans un cadre législatif aux contours assez flous, et adopte une philosophie dont l'universalité est sujette à flexibilité dans le sous-continent indien. Il n'existe pas encore à proprement parler de comité national d'éthique pour le sida; aussi les dérapages en matière des droits les plus élémentaires (droit à la dignité, au respect de l'individu ou d'un groupe particulier) sont monnaie courante, y compris sous couvert de scientificité (l'individu en danger devient dangereux pour les autres).

Peu d'informations sur le cadre juridique de la recherche à caractère appliquée sont immédiatement accessibles en Inde, si ce n'est qu'un certain nombre de conflits surviennent entre chercheurs et commanditaires, les premiers se plaignant de la non maîtrise de leurs résultats, en particulier lorsqu'il s'agit de bailleurs de fonds internationaux. L'existence de procédures en justice ont été évoqués (problème de paiement, délai) mais rien ne peut être affirmé avec précision. La remise en cause de la propriété intellectuelle du travail ne se restreint pas à une affaire entre le chercheur et le sponsor mais de nombreux litiges, vite étouffés, surviennent au sein même d'une institution de recherche, entre professeur et étudiants, entre responsables de projets et collègues subordonnés. Une autre source de conflits a trait à la confidentialité des enquêtes compilées par l'état. La recherche sociale sur le sida est investie d'un caractère secret car c'est un sujet sensible aux implications politiques gênantes. Un haut fonctionnaire du pays Tamoul affirmait qu'il ne pouvait pas disséminer publiquement les résultats d'une enquête nationale sur les comportements sexuels vu « l'embarras » pour un gouvernement d'avoir à justifier l'utilisation des deniers publics afin de « savoir seulement ce qui se passe dans le lit des gens (sic) ». En contrepartie, le problème de la non divulgation des résultats pose problème en ce sens qu'elle n'est plus soumise à critique ni à vérification. Une association des droits de l'homme s'est farouchement opposé à cette « raison d'état » qui s'extrapole à ce que d'aucuns appellent l'ingérence des agences extérieures : en 1996, ledit responsable des droits de l'homme s'attaqua à la décision arbitraire d'une organisation internationale de lancer un vaste projet de prévention sur des populations ciblées qui selon toute évidence avaient été arbitrairement sélectionnées. Décision estimée discriminatoire, issue des conclusions formelles d'une recherche entourée d'un halo mystérieux et dont personne n'avait accès.

Les questions qui touchent à l'éthique au temps de l'épidémie concernent et sensibilisent davantage le monde de la recherche, même si aucun consensus n'existe entre chercheurs, et encore moins entre chercheurs en sciences sociales, développeurs et médecins. Souvent les conditions dans lesquelles s'effectuent les recherches comportementales violent les recommandations de la déclaration d'Helsinki de 1964 (modifiée à Tokyo) en matière d'éthique médicale. Il arrive que le recueil de données socio-démographiques ne respecte pas l'anonymat des personnes, que ces dernières subissent les préjudices une fois identifiées; autant d'attitudes qui font oublier que, d'après le manifeste de Tokyo, les intérêts du sujet doivent passer avant ceux de la science et de la société. C'est ainsi qu'en Tamil Nadu, les personnes qui viennent se faire traiter dans la majeure partie des hôpitaux publics pour une MST (y compris ceux infectés par le virus) doivent obligatoirement répondre à un questionnaire nominatif inquisiteur avant d'être acceptées en consultation. Une anecdote qui nous est arrivée est non moins emblématique d'un manque de conscience éthique: alors que nous cherchions à obtenir des détails sur les caractéristiques socio-économiques de la population atteinte par le sida, nous reçûmes, en sus (sans l'avoir sollicité) des informations demandées, une liste avec noms et adresses complètes des personnes concernées.

Les exemples montrant les abus dangereux des pratiques de la recherche en sciences sociales pourraient être multipliés à l'infini. Néanmoins, un certain nombre de principes idéaux qui la commandent sont en général partagés par les chercheurs. Un d'entre eux stipule qu'il ne peut y avoir d'implantation sérieuse sans connaissance préalable des phénomènes sociaux qui conditionnent la vie en société. Toute action s'inscrit dans un espace circonstancié et dans un contexte socioculturel à l'intérieur desquels il s'agit d'identifier des *faisceaux de relations*. On déplorera cependant que la communauté des chercheurs en Inde, hétérogène, n'attribue pas la même signification au terme social (*Cf. in part one : on understanding and action*).

L'écart se creuse encore davantage entre spécialistes et non spécialistes des comportements humains qui ne parlent plus du tout de la même chose quand les derniers confondent la recherche en sciences sociales avec le travail que réalise un assistant social, un travailleur communautaire.

Le dénominateur commun des principes sous-jacents à la relation entre recherche et action peut se réduire à un petit nombre d'idées majeures. Tout le monde s'accorde à dire qu'une recherche a pour ambition d'établir une cartographie du social, de révéler des faits, et, plus encore, des *relations* entre les faits jusqu'alors insoupçonnés, de mettre à jour les forces sociales, économiques et culturelles (mais aussi les fractures et les points de vulnérabilité) qui influent sur les comportements individuels. Plus important d'un point de vue anthropologique: c'est la compréhension des mécanismes de l'altérité qui est en jeu. Il faut observer à cet égard que cette idée fondamentale s'exprime non sans peine dans les présentations et discussions du séminaire de Pondichéry. Très souvent, les chercheurs ont du mal à énoncer clairement l'existence de l'altérité et savent encore moins faire valoir ce concept quand ils s'adressent à des gens qui ne sont pas de leur discipline.

Un équivoque : l'action a pour objectif de susciter des modifications mues par des forces extérieures qui, sommes toutes, impliquent une irruption violente dans la vie de l'autre. C'est pourquoi il est nécessaire de cerner les enjeux de l'altérité, de comprendre ce qu'elle implique comme challenge pour les populations concernées. Une recherche a également pour objectif d'aborder un fait dans sa totalité - par conséquent de comprendre les interactions entre les multiples facettes qui conditionnent la vie en société - et de ne pas le traiter isolément, au risque de n'observer que les symptômes au détriment de l'ensemble du système. Or, ces interactions symboliques - ce système de relations plus ou moins arbitraire qui légitime et qui donne sens aux fondements de la société (rapport homme/femme, perception des fluides et de la sexualité, etc.) - constituent autant de leviers qu'il devient plus facile de rompre une fois mis à jour.

Il va de soi que ce petit nombre d'idées fortes, généralement partagées par la communauté des chercheurs, se complète par des variantes qui ne font pas l'objet d'un consensus, principalement quand est abordée la dimension utilitaire de la recherche. Comme le rappelle Gérard Lenclud, mettre ses connaissances au service d'un programme d'action, qui est une transformation planifiée, suppose une acceptation minimale des visées, nécessairement entachées d'ethnocentrisme, élaborées par l'institution, nationale ou internationale qui met en oeuvre ce programme, une reconnaissance des motifs. Il s'agit pour le chercheur d'apporter non des schémas mais une perspective (Lenclud, 1995 : 82-83). Jean François Baré explique que la position de la France à l'égard de la recherche anthropologique appliquée se trouve entre l'écorce et l'arbre (Baré, 1995), métaphore qui lui sert à illustrer le paradoxe à soutenir - comme certains le font - que la discipline anthropologique est une connaissance mais qu'elle ne doit servir à rien ni à personne sinon par le truchement des écrits indigestes pour le commun des mortels. Dans le contexte indien, le problème ne se pose pas avec autant d'interrogations épistémologiques mais il est indéniable que la raison utilitaire de la science ne va pas toujours de soi.

Suite aux discussions avec des collègues indiens, c'est surtout la manière dont la recherche est récupérée, interprétée qui pose problème et incite le chercheur à envisager les risques de détournement de ses travaux. Doit-on dire tout ce que l'on sait ? Y-a-t-il des révélations que l'on fait qui risquent de porter préjudice aux populations ? Dans la lecture d'un rapport scientifique, le commanditaire peut avoir une double lecture et en retirer seulement ce qu'il avait déjà pressenti. Il peut aussi accentuer certains faits et ne pas prendre en compte d'autres, plus dérangeants. En somme effectuer un tri. Quelle est la part de l'engagement du chercheur à cet égard ? Doit-il anticiper et par conséquent s'informer des logiques institutionnelles auxquelles sera inéluctablement confronté ? L'on se rend compte finalement que les incompréhensions sont en partie conditionnées par la présence de deux mondes qui coexistent mais ne collaborent pas dans la durée.

Dans les critiques faites à l'égard de l'applicabilité des sciences humaines, ce sont plus souvent les conditions et les circonstances dans lesquelles elles se déroulent plutôt que les applications en tant que telles qui sont remises en question: les chercheurs indiens présents à l'atelier se plaignaient des contraintes qui leur étaient imposées en terme de temps (un mois pour faire une évaluation), de logistique, d'encadrement. Or, une discipline comme l'anthropologie qui se définit avant tout par sa méthode plutôt que par son objet (qui est l'homme dans sa totalité) doit certes ne pas accepter des compromis qui trahiraient sa validité et sa rigueur, mais peut-être doit-elle se forcer à sortir de ses gongs en rendant plus accessibles les acquis de son savoir à ceux qui, ne possédant pas les outils de la science, font fait la démarche de solliciter le chercheur. La première obligation est une exigence de lisibilité. Là n'est pas la chose la plus simple dans la mesure où il est plus facile de se faire comprendre par son homologue (même jargon, idées partagées) que par une personne d'une compétence différente. La seconde règle concerne l'intégrité du chercheur. Des participants à Pondichéry se plaignaient de ne pas pouvoir entreprendre une recherche comme bon leur semblait, soit qu'ils étaient soumis à des présupposés idéologiques, soit qu'ils devaient aboutir à un résultat affiché d'avance par le commanditaire. Si l'indignation est légitime, l'irresponsabilité ne l'est pas. Il est impératif

d'avoir le courage de refuser un compromis qui transforme une activité scientifique en une industrie de marketing-conseil de bas prix. Une recherche est par définition ouverte, peut faire surgir des faits inattendus et ne peut être préconditionnée.

Les champs d'investigation

Un type de recherche largement dominant sont les études d'évaluation. Ces dernières sont arbitrairement distinguées en pré-évaluations, post-évaluations, évaluations continues ou semi-continues. Des instituts scientifiques comme l'IIPS de Mumbai ont conduit avec intelligence de nombreuses évaluations à la demande d'agences diverses mais comme l'indique S. Surender (Cf. part 4), trop de ces travaux s'effectuent d'une manière routinière et sans outils vraiment adaptés. Il n'existe pas de tentative de mise au point d'indicateurs spécifiques. Rares ou superficielles sont les études qui sont parvenues à proposer une méthode solide pour évaluer le niveau de participation communautaire, un changement durable. Les demandes d'évaluation *a posteriori* sont les plus courantes et la plupart des récipiendaires ne savent pas clairement ce que l'on attend d'eux : évaluer un processus, faire un bilan, montrer un impact ? Par contre il n'est pas rare que la réponse qu'on attend d'une évaluation soit tacitement posée en préambule. Le chercheur est plutôt perçu comme un simple technicien, un opérateur, un programmeur, que comme un individu qui pense à travers le corpus de sa discipline.

Plus regrettable encore : les évaluations sont unilatérales. Il est davantage demandé aux études de circonscrire les problèmes inhérents à la communauté que ceux liés au fonctionnement des programmes. C'est rarement le projet ou son implantation qui est en cause, mais l'apathie et l'incompréhension des populations. Pour paraphraser Bernard Hours, tout ce passe comme si l'on disposait des bons programmes, des bons bailleurs de fonds, des bons travailleurs sociaux et des bons responsables de projet, mais pas des bonnes populations. La stratégie consiste alors à trouver « le truc » pour modifier les comportements individuels et communautaires, sans pour autant regarder ce qui se passe du côté des développeurs. Ce qu'élabore une ONG, c'est avant un dispositif, une organisation d'où découle une relation sociale entre les acteurs du développement et une communauté. Or dans une évaluation, la qualité de cette relation sociale intéresse peu ou prou.

Si l'utilité de l'évaluation est reconnue par tous les bailleurs de fonds, il n'en va pas de même pour des études compréhensives qui ont pour objectif principal de fournir une interprétation la plus fidèle de la vie en société (Il s'agit pourtant d'une évaluation idéale). Jusqu'à présent, les responsables indiens n'encouragent pas de longs travaux dont ils doutent de l'aboutissement. Politiciens et décideurs exigent autre chose d'une étude : une certaine représentativité, un nombre d'enquêtes suffisamment élevé pour auréoler les résultats d'une quelconque validité. Il y a donc un net encouragement à promouvoir les informations quantifiables, au détriment de la mise en évidence de relations déterminantes entre des phénomènes apparemment sans lien mais dont des études fines ont prouvé la pertinence (distension des liens socio-familiaux et comportements individuels à risque, endettement familial et prostitution).

Force est de reconnaître la complexité de la relation entre chercheurs et commanditaires dans la mesure où les logiques qui pour le premier valident sont étude ne sont pas celles qui accrédièrent ladite recherche aux yeux du second. Les éléments qui attestent d'une rigueur scientifique ne sont pas ceux que regarde forcément un homme qui intervient sur le terrain ou dans la prise de décision. Si les regards peuvent se croiser - heureusement c'est parfois le cas - la prise en compte des acquis d'une recherche, aussi solide soit-elle, n'est pas aussi simple qu'il n'y paraît : c'est peut-être là une naïveté de chercheur de croire que tout devrait aller de soi après ses travaux scientifiques. Celui qui agit et planifie est soumis à des pressions ignorées ou sous-estimées par le chercheur (faisabilité, acceptabilité). Il doit également affronter des contraintes institutionnelles qui impartissent dans sa prise de décision.

Signalons enfin que les conditions d'implantation des programmes de prévention du sida font partie intégrante de la recherche en sciences sociales qui se concentre désormais sur la méthodologie dans l'intervention. Une part non négligeable de la recherche devient par conséquent didactique et s'oriente, en ces temps d'épidémie, sur les conditions d'applicabilité des actions, sur les modalités de passage de la théorie à la pratique.

Les orientations actuelles

Très inégales et souvent décontextualisées dans les premiers temps, les études récentes tendent à s'éloigner des enquêtes standardisées et à se diversifier par leur problématique et leur méthodologie. Un recensement des acquisitions scientifiques sur le thème du sida en Inde nécessiterait de faire l'objet d'une analyse en soi. Notons, sans répéter ce qui n'a pas été dit auparavant (Bourdier, [part 4](#)) que des agences internationales comme les Fondations Ford et Rockefeller encouragent d'excellentes études innovatrices qui élargissent la thématique du sida en intégrant des domaines telles que la construction de la sexualité chez les hommes et les femmes, les rapports de genre, les processus de négociation sexuelle au sein du couple, les stratégies de recueil d'information sur la sexualité chez les jeunes (à défaut d'éducation familiale et institutionnalisée), les formes de communication non verbale, l'expression des notions de désir et de plaisir (concept révolutionnaire en Inde quand on parle de sexualité !), community's capacity building, men and women empowerment, people's perceptions of reproductive health and their consequent sexual behaviour, la négociation sexuelle au sein du couple et de la famille élargie, comportements sexuels chez les populations non mariées en milieu rural, pour ne citer que les principaux.

Plutôt que reprendre des idées débattues au cours du séminaire, on se propose ici de citer quelques données de la réalité sociale qui en Inde sont enclines à motiver des recherches. Un des thèmes autour duquel gravitent certaines recherches est la question brûlante du test sida à l'occasion du mariage. Sans aborder la question de la légitimité, des enquêtes, à commencer par les nôtres, montrent que le souci de connaître le statut sérologique du partenaire devient une préoccupation majeure des jeunes filles, indépendamment de la volonté de leurs familles. Il serait nécessaire de creuser le problème afin de mettre en avant les facteurs sociaux qui induisent ces motivations qui selon toute apparence se rapporteraient en partie aux pratiques matrimoniales. Par ailleurs, le concept de confidentialité est plus que jamais évasif en ces temps d'épidémie. Peu reconnaissent, y compris dans le monde des chercheurs, qu'elle est une affaire strictement privée. Le seul argument qui joue en faveur de la divulgation « à tout prix » de la séropositivité d'une personne dans sa famille est que le non partage de l'information aboutit à l'auto-exclusion qui peut aller jusqu'au suicide. Des membres d'associations de séropositifs affirment que la solitude face au pesant secret est une des pires choses qu'ils aient enduré. Dans ce contexte, force est de reconnaître qu'aucune étude en Inde n'a cherché à étudier les mécanismes d'auto-exclusion (tout le monde ne parle que d'exclusion sociale) et personne encore n'envisage de se pencher sur la mitigation du phénomène d'auto-rejet par le suivi affectif des individus infectés.

Notons pour finir une sélectivité des phénomènes que la recherche étudie. Autour du sida, des discours se cristallisent à propos de certains faits jugés préoccupants (sexualité, modalité de prise en charge communautaire des malades, rôle des ONG pour l'acceptation des préservatifs), alors que d'autres problématiques passent quasiment inaperçues (contrôle du sang, infection par le lait maternel, politiques publiques).

Lieux et circonstances de rencontre entre chercheurs et acteurs du développement

Les participants font valoir que le travail d'un chercheur s'arrête à la remise d'un document qui lui a été demandé. Après il n'en conserve pas la maîtrise. Cependant les conseils et les recommandations se réduisent à des illusions s'ils ne sont pas suivis d'une argumentation claire montrant comment il est possible d'intégrer les acquis d'une recherche dans un projet en cours. En effet, une question récurrente chez les acteurs du terrain est « tout cela est très bien, mais comment le faire valoir dans mon projet ? ». On est en droit de se demander si, une fois engagé, le chercheur n'est pas en devoir de répondre à cette question tant que le contenu lui semble impartial.

La difficulté des chercheurs à convaincre leur auditoire, en évitant un jargon compris par une minorité, est un obstacle non négligeable pour les retombées de leurs études. Il est de bon ton dans le milieu de la recherche, et ceci n'est pas restreint à l'Inde, de se plaindre de ne pas être compris, de ne pas être écouté. Il serait plus constructif d'adopter une attitude inverse et de se poser les questions autrement : qu'avons-nous appris qui puisse avoir une implication au niveau de la politique de prévention et des programmes en place ? Quelles sont les stratégies potentielles de dissémination qu'il mériterait d'explorer à cet égard ? Etant donné que ce livre fait suite à un atelier où la notion de réseau a été discutée, on se restreindra à une analyse critique de ces deux possibilités de rencontre.

Les réseaux

Depuis l'avènement du sida en Inde, il n'y a pas un réseau mais une pléthore de réseaux aux motivations différentes. On remarque que le concept de réseau a un sens restreint : le plus souvent c'est un ensemble de personnes travaillant dans la même profession (ONG, administrateurs, professeurs) mais pratiquement jamais un regroupement d'institutions ou d'individus d'horizons divers conviés à réfléchir autour d'une question commune. Dans

la pratique, la constitution d'un réseau est éminemment stratégique: il s'agit moins d'échanger des idées, des compétences que de renforcer un esprit de groupe afin d'obtenir des fonds, afin de s'opposer à un adversaire commun (un autre groupe d'ONG, le gouvernement) que de s'unir pour améliorer le bien-être de la population. Les réseaux élaborés dans le Tamil Nadu depuis l'avènement du sida facilitent au plus l'accès à l'information internationale et nationale, permettent de mettre en perspective les stratégies et les plans d'actions de programmes locaux mais ont rarement pour objet de disséminer les résultats, encore moins de fournir des informations clés aux autres.

Les ONG qui sont financées par une agence internationale particulière n'ont pas de lien avec celles qui bénéficient d'une autre source de financement. Dans le Tamil Nadu, un certain paternalisme se tisse entre le gouvernement indien et les associations qui bénéficient de son aide tandis que celles en dehors des circuits étatiques s'érigent en lobby contre la politique nationale. Aucune tentative de concertation n'a jusqu'à présent été proposée, aucune plate-forme commune n'existe. Les différents réseaux (dont l'adhésion est contrôlée) ne sont pas connectés entre eux, si ce n'est pour des échanges d'informations superficielles. Un réseau se caractérise tant par son sa dimension inclusive que son caractère d'exclusion.

L'élaboration de réseaux correspond fréquemment à une tentative de domination et d'absorption de petites associations par une plus grande. Théoriquement un tel regroupement peut s'avérer nécessaire et légitime, ne serait ce que pour pallier à une trop grande atomisation des projets. Ce peut être aussi salvateur quand une agence privée - tel est le cas en Tamil Nadu - décide de regrouper une trentaine d'organisations sans financement et de les promouvoir personnellement. Toutefois plusieurs ONG modestes disent en avoir essuyés les frais : leur dépendance a été accrue et elles ont le sentiment d'avoir été reléguées à des organisations subordonnées, de simples sous-traitants à la marge d'initiative extrêmement réduite.

On ne peut nier que la promotion, aussi sauvage soit-elle, des mini-réseaux aie permis à de nombreuses personnes de recevoir une formation, d'élargir leur compétence, de rencontrer leurs homologues. Quelques forums ont indiscutablement généré des interactions, suscité des dynamiques nouvelles pour le développement des programmes d'action. Il n'empêche que l'ambiance générale est à la suspicion et rares sont les organisations qui acceptent désormais de se constituer en réseaux, en dehors de ceux, informels, qui reposent sur l'amitié, la connivence ou de ceux réunissant des individus ayant des intérêts en commun.

Les spécialistes des sciences sociales ne sont pas en relation avec les réseaux d'ONG et n'ont pas, jusqu'à présent, été sollicités par les institutions gouvernementales (TNSACS) pour participer de manière durable à la mise en place de projets. Il existe une séparation claire entre chercheurs, qui ont leurs propres réseaux, et développeurs qui font de temps en temps appel aux premiers mais de façon sporadique et ponctuelle. Au bout du compte la notion de réseau, toujours menacé de récupération, devrait se comprendre dans un sens plus large et être *pluridisciplinaire* par essence. Un changement s'impose : Internetworking serait le concept approprié et signifierait à la fois intégration et instauration d'une plate-forme commune pour générer les discussions, faciliter des collaborations. Les enjeux d'intérêts personnels ne peuvent y avoir de place. La complémentarité des expériences et des connaissances est la seule manière de renforcer un dispositif d'action qui par définition nécessite des compétences différentes. La participation des chercheurs est incontournable pour parvenir à cette fin.

Les colloques et les ateliers

Les séminaires de dissémination à l'image de ceux encouragés par USAID, la Fondation Ford ont l'avantage de présenter les résultats d'une recherche à la critique. Ils demeurent encore rares. Les espaces de rencontre informels que sont les ateliers comme le nôtre sont initialement prévus pour favoriser la communication, faciliter la dissémination des connaissances, générer des débats, connecter les gens entre eux, susciter des amitiés (et inimitiés), promouvoir de futures collaborations. Des gens de compétence différentes sont conviés à réfléchir ensemble, pour un moment, sur des questions communes mais que chacun aborde avec un angle particulier. Un certain nombre de participants à Pondichéry habitués à fréquenter de telles manifestations manifestent leur doute quant aux retombées théoriques et pratiques d'un séminaire. Trouver un terrain d'entente et de compréhension ne va pas de soi. Tenter de montrer la pertinence d'une étude sociale auprès de politiciens et d'administrateurs s'avère de la gageure pour la plupart des scientifiques qui en ont fait l'amère expérience. Leurs tendances actuelles serait plutôt de plaider pour un discours avec certains interlocuteurs de la population (les jeunes par exemple, les community based organizations, les ONG). D'autres au contraire disent qu'il est nécessaire de continuer à communiquer avec les représentants du gouvernement mais de s'adresser non pas au sommet de la hiérarchie, mais à ceux qui sont plus proches des

actions de terrain à l'image des Programme executors, des National Service Scheme officers, et plus en mesure d'établir des liens entre recherche et politique d'intervention.

Pour beaucoup, un atelier est un moyen de sortir de l'isolement. La littérature sur le sida abonde en Inde, mais les jeunes chercheurs ainsi que des représentants d'ONG n'y ont pas facilement accès. Les livres existent mais sont chers et parfois difficiles à obtenir. Il est pourtant à déplorer que l'accès aux réunions n'est pas uniforme pour tout le monde. Dans la myriade des colloques nationaux et internationaux organisés dans le pays, une sélection s'effectue par la disponibilité financière (les droits d'entrée peuvent être exorbitants : plusieurs centaines de dollars pour un étranger lors d'un symposium à Chennai en 1997), la notoriété, l'intérêt potentiel que peut symboliser une personne. Rares sont les individus quotidiennement confrontés aux populations à avoir l'opportunité de participer à des séminaires. Ce sont leurs supérieurs qui y vont. Les premiers qui sont pourtant les promoteurs de base du développement et de la prévention auraient pourtant beaucoup de choses à dire sur la réalité sociale, l'expérience vécue des groupes auprès de qui ils travaillent. Même s'ils viennent, la hiérarchie spatiale de l'organisation les pousse dans les recoins sombre d'une salle où la prise de parole est un exploit, voir un défi tant que leur supérieur hiérarchique est également dans la pièce. Ceci explique, en partie, le manque crucial de données, d'informations de première main et d'expériences directes en faveur des discours incantatoires qui, entre guirlandes, dévotions, cadeaux et remerciements à n'en plus finir, constituent les arcanes indispensables de la réussite formelle d'un « bon » colloque onéreux.

Se pose aussi le problème de la momentanéité. Chacun reprend ensuite la position qu'il occupe dans la société. Après notre séminaire, des contacts se sont effectués, des relations se sont prolongées entre certains des invités, mais loin s'en faut de constater un changement dans la perspective de tout un chacun. Un responsable du déroulement des programmes d'ONG, intéressé par l'idée de réunir chercheurs et gens dans l'action, a décidé d'organiser, au sein de l'institution gouvernementale qu'il représente, des rencontres régulières de ce genre. En dehors de cette dynamique heureusement éveillée, quel suivi aura le séminaire en dehors d'une publication qui sera lue par une minorité ? Peut-être rien. Quelles illusions entretenons-nous ? Peut-être celle que Gérard Lenclud entrevoit quand il rappelle que l'application, considérée ici comme l'opération consistant dans le transfert de concepts et d'énoncés en provenance de la science pure dans le domaine de la technique, ne serait pas une activité localisable, isolable. Un savoir est mis à la place d'un dispositif d'action, mais la limite entre les deux ne peut se définir clairement. Le but n'est d'ailleurs pas d'épiloguer sur le tracé de la frontière mais plutôt de soumettre un ensemble de connaissances à d'autres qui, les découvrant avec un oeil critique, décident ce qu'ils peuvent en faire.

